# Genetic Tests and Health Insurance: Results of a Survey

*Background Paper*

Congress of the United States
Office of Technology Assessment

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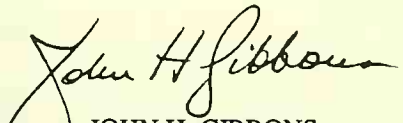
# Foreword

As we increase our knowledge of human genetic diseases and improve our ability to diagnose and predict them, concern about denial or restriction of health care insurance is often raised. Yet little is known about either health insurers' attitudes toward reimbursement for genetic tests or policies for using test results in underwriting. To assess these views and practices, OTA surveyed commercial insurers, Blue Cross and Blue Shield plans, and health maintenance organizations that offer individual or medically underwritten group policies.

OTA undertook the survey in support of its assessment *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening*, which was published in August 1992. That report—requested by the House Committee on Science, Space, and Technology, the House Committee on Energy and Commerce, and Representative David R. Obey—focuses on survey results specific to cystic fibrosis carrier screening. This background paper summarizes information about cystic fibrosis and presents additional results that pertain to the broader topic of health insurers' practices and attitudes toward genetic information and genetic tests for diseases other than cystic fibrosis. It presents survey findings related to:

- how health insurers view information from various sources—e.g., genetic tests, other medical tests, or family histories—in underwriting decisions;
- current and future policies toward reimbursing consumers for the costs of genetic tests; and
- expectations about the impact and use of genetic tests and genetic information on health insurance.

OTA was assisted in preparing the survey instrument and background paper by a panel of advisors, contractors, workshop participants, and reviewers selected for their expertise and diverse points of view. We gratefully acknowledge the contribution of each of these individuals. OTA, however, remains solely responsible for the contents of this background paper.



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NOTE: OTA is grateful for the valuable assistance and thoughtful critiques provided by the advisory panel members. The panel does not, however, necessarily approve, disapprove, or endorse this report. OTA assumes full responsibility for the report and the accuracy of its contents.

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# Chapter 1
# Introduction

Health insurance in the United States is not monolithic. U.S. health care financing, which totaled more than $800 billion in 1991, is a mixture of public and private funds. For the majority of Americans, however, access to health care—and the health insurance that makes such access possible—is provided through the private sector. Privately financed health insurance for medical expenses covers more than 189 million persons through self-funded companies, commercial insurance companies, Blue Cross and Blue Shield (BC/BS) plans, and managed care programs (e.g., health maintenance organizations (HMOs) and preferred provider organizations) (1). Among these entities, business practices vary widely within and among the categories, and each is subject to different State or Federal regulations (2).

The majority of Americans obtain health insurance through employment—either directly as employees or as family members of the employed. Most people covered in this manner obtain health insurance as members of large groups, with no diagnostic tests or physical examinations required for entry (i.e., no medical underwriting). Some individuals, however, obtain health insurance through small groups, which require some diagnostic tests or physical examinations, on which the insurance contract's coverage and costs are based. Finally, persons without group coverage can seek individual health insurance from commercial insurers, BC/BS plans, or HMOs.

Organizations that medically underwrite individual or group policies classify risks on actuarial data. Currently, about 10 to 15 percent of individuals with health care coverage are medically underwritten. This selection process—i.e., differentiation based on medical characteristics—is an integral part of the insurance mechanism. Risk classification is the foundation, in fact, for the concept of private insurance.

In the coming years, an increasing number of underwriting decisions and reimbursement policies will revolve around the tests, information, and services arising from the Human Genome Project. The number of DNA-based tests for genetic disorders and predispositions will almost certainly expand by an order of magnitude in the next decade. How insurers view such tests will affect their utilization. This background paper describes results from a 1991 OTA survey of U.S. health insurers' attitudes toward genetic tests and genetic information—both how they currently view information from various sources (e.g., genetic tests, other medical tests, or family histories) in underwriting decisions and how they might reimburse consumers for genetic tests. It also reports data on the role health insurers expect genetic tests and genetic information will play in their business practices over the coming decade.

## HEALTH INSURANCE AND GENETICS

Perhaps the most widely raised social question stemming from the Human Genome Project is what effect genetic tests have (and will have) on health care access in the United States. Consumers fear exclusion from health care coverage due to genetic, or other, factors. Because health care access involves private health insurance for most citizens, concern focuses on this market.

Some commentators speculate that, overall, genetic analyses will mean fewer people will have access to private health insurance because such tests identify or refine risks. They argue genetic tests, in precluding more and more people from health insurance, will provide the best reason yet for a nationalized health care system. Others contend, however, that genetic assays could rule out an individual's risk for a disorder and hence increase access to health care coverage. That is, making use of genetic information would allow insurers to better assess risks, with the result that individuals at elevated risk will pay more (or be denied access), but people with low risk will pay less. Still others point out that as the number of identified genes increases, so will the number of people who will be identified as at risk, which could spread risk. The ultimate impact of genetic tests, then, will depend, in part, on the practices and attitudes of insurers toward tests for genetic disorders, as well as the morbidity and mortality associated with particular conditions (2).

## SCOPE AND ORGANIZATION OF THIS BACKGROUND PAPER

For its assessment, *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening* (2), OTA found a paucity of information about health insurers' current attitudes and policies toward genetic tests or any future role such tests might play in their business practices. To gain some understanding about these issues, OTA surveyed commercial insurers, BC/BS plans, and selected HMOs that offered individual or medically underwritten group policies in June 1991. This survey did not extend to large group contracts or to the practices and attitudes of self-funded companies, which cover the largest percentage of individuals who have private health care benefits.

Results from OTA's survey of health insurers apply to a small slice of the insured population—the 12.7 million people who have individual or medically underwritten group coverage provided through survey respondents. Further, most of the information presented in the following chapters should not be construed to represent either the numbers or percentages of commercial entities, BC/BS plans, or HMOs that have dealt with the issues presented. Respondents were asked how they *would* treat certain conditions or scenarios presented (currently or in the future, depending on the questions), not whether they, in fact, *had* made such decisions.[1]

This background paper reports the complete results from OTA's survey of health insurers, but does not analyze them in a public policy context. That analysis is presented in the aforementioned report for which this survey was undertaken (2). Chapter 2 of the background paper describes general characteristics of the respondents and the populations they serve. Following this, data related to genetic tests, genetic information, and underwriting are discussed in chapter 3. Chapter 4 presents data about health insurers' policies toward reimbursing consumers for various genetic tests and services, and chapter 5 examines insurers' overall attitudes toward current and future use of genetic tests and information. Appendix A details the survey method, including population selection, and appendix B presents verbatim comments made by respondents in space provided for open ended statements. Survey instruments are reproduced in appendix C.

## CHAPTER 1 REFERENCES

1. Health Insurance Association of America, *Source Book of Health Insurance Data 1991* (Washington, DC: Health Insurance Association of America, 1991).
2. U.S. Congress, Office of Technology Assessment, *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening*, OTA-BA-532 (Washington, DC: U.S. Government Printing Office, August 1992).

[1] In a few instances, as evident through question wording, OTA did ask about an actual practice—e.g., "To your knowledge, has your company ever reimbursed for carrier testing for cystic fibrosis?" As is clear from the survey questionnaires reproduced in appendix C, however, most questions inquired about how the respondent "would" treat a given situation.

# Chapter 2
# Profile of Respondents

In 1991, OTA conducted a survey of commercial health insurers, Blue Cross and Blue Shield (BC/BS) plans, and health maintenance organizations (HMOs) as part of its report, *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening* (4). The survey collected information on insurers' underwriting practices and use of medical screening for individual and medically underwritten group policies. Additionally, it sought information about how insurers view and use genetic information and genetic tests, especially DNA-based tests for cystic fibrosis (CF) mutations. A 1986 OTA survey targeted a similar population, but the data collected for that survey focused on general medical testing (especially for the human immunodeficiency virus (HIV)), and did not examine genetic tests and genetic information (3).

## RESPONDENT PROFILE

General industry profile questions asked by OTA included the number of people respondents insure in their plans, the number of applications received, and how those applications were rated. This chapter presents such data for each of the three populations OTA surveyed.[1] Appendix A describes how the population samples were derived.

### *Commercial Health Insurers*

In the United States, approximately 1,250 for-profit companies are in the business of writing major medical expense policies (2), but increasingly few health insurers write policies for individuals or medically underwritten groups (4). Of 225 commercial health insurers initially mailed a survey, 81 insurance companies responded that they offered neither individual nor medically underwritten group policies. Of the 51 responding companies that did offer such policies, 29 companies offered individual coverage, 37 respondents offered medically underwritten group policies, and 15 companies offered both (table 2-1). Thirty-eight companies also wrote disability insurance, and 42 wrote life insurance. None of the companies included Medigap policies or statistics in their responses. (Medigap policies are designed to supplement Medicare coverage for the elderly.)

As an aggregate population, responding companies reported receiving a total of 940,745 applications for individual health insurance in 1990. The annual volume of applications ranged from 50 to 368,350 applications per company (table 2-2). Four companies alone accounted for 564,475 applications, or more than half the annual volume of the entire survey population. Responding companies reported receiving 625,134 applications for medically underwritten group coverage, with a range of 100 to 100,000 applications. Responding companies reported insuring a total of 2 million people under individual policies, and 2.3 million under medically underwritten group policies (table 2-3).

Companies also were asked to indicate the distribution of persons they covered under self-funded administrative policies, individual policies, medically underwritten groups, and large groups. All respondents had business encompassing these practices, but the proportions among companies varied widely.

The client mix within any single responding commercial insurer varied. People covered under self-funded administrative policies comprised between 1 and 70 percent of clients covered by commercial respondents, with an average of 25 percent. Two to 100 percent of persons were covered through individual policies, with an average of 50 percent. The percentage of persons who were covered under medically underwritten group policies of commercial insurers ranged from 1 to 100 percent and averaged 62 percent. Finally, commercial insurers responding to the OTA survey covered 6 to 96 percent of people under large group policies, with an average of 44 percent.

### *Blue Cross and Blue Shield Plans*

Surveys were sent to both the medical director and the chief underwriter for 72 of the 73 BC/BS plans. (Puerto Rico's plan was excluded.) BC/BS plans often operate under considerably different condi-

[1] For chapters 2 through 5, the numbers in the text might not total 100 percent or sum to the actual number of responses for a particular survey population because "no response" is not included in the discussion, but is presented in the table.

**Table 2-1—Respondent Profile: Companies That Offer Individual or Medically Underwritten Group Coverage**

| | Commercial insurers (n = 51) | BC/BS plans—underwriters/ medical directors (n = 29/18) | HMOs (n = 23) |
|---|---|---|---|
| Individual policies | 29 companies | 25/18 plans | 11 HMOs |
| Medically underwritten group policies | 37 companies | 21/15 plans | 20 HMOs |
| Nongroup/open enrollment | NA | 8/7 plans | NA |

NA = Not applicable.

SOURCE: Office of Technology Assessment, 1992.

**Table 2-2—Number of Applications Received by OTA Survey Respondents**

| | Commercial insurers | BC/BS plans—underwriters/ medical directors | HMOs |
|---|---|---|---|
| Individual policies | 940,745 (range: 50 to 368,350) | 261,186/303,692 (range: 512 to 47,380)/ (range: 9 to 120,000) | 69,554 (range: 24 to 43,000) |
| Medically underwritten group policies | 625,134 (range: 100 to 100,000) | 103,726/101,391 (range: 1,200 to 19,000)/ (range: 0 to 34,000) | 414,977 (range: 150 to 350,000) |
| Nongroup/open enrollment | NA | 29,360/13,768 (range: 60 to 25,000)/ (range: 0 to 6,168) | NA |

NA = Not applicable.

SOURCE: Office of Technology Assessment, 1992.

tions from commercial carriers. Some plans hold open enrollment periods, all are regionally based, and many enjoy significant shares of their local health insurance market. These factors play a pivotal role in underwriting policies. Twenty-nine chief underwriters completed a survey and 18 medical directors returned surveys. Some overlap exists between the two populations, so the reported data are not additive, but are treated as two populations.[2] In addition to inquiring about medically underwritten groups and individuals, the BC/BS survey instrument asked how the questions applied to a third category: nongroup open enrollment policies.[3]

Of the 29 BC/BS plans represented by the underwriter survey, 25 of 29 write individual policies and 21 of 29 offer medically underwritten group policies. Eight of 29 BC/BS surveys returned by chief underwriters represented plans that offer open enrollment; each of these eight offers continuous, year-round open enrollment (table 2-1).

All 18 BC/BS plans represented by the medical director survey write individual policies, and 15 plans also offer medically underwritten group policies. Seven represented plans that offer continuous, year-round open enrollment. Twelve States require BC/BS plans to offer an open enrollment period—i.e., all applicants must be accepted for coverage regardless of their health status and with no medical underwriting. Three BC/BS plans represented by the underwriter survey also provide disability insurance and six wrote life insurance; 1 plan represented by the medical director survey also provides disability insurance and 1 wrote life insurance.

The responding BC/BS plans represented by the underwriter survey received 261,186 applications for individual health insurance in 1990, with a range of 512 to 47,380 applications. The medical director sample revealed that 303,692 individual insurance applications were received by these respondents, with a range of 9 to 120,000. BC/BS underwriters

[2] Because anonymity and confidentiality were guaranteed, OTA does not report the actual number of policies that overlapped, nor did OTA perform a comparative analysis between the underwriter and medical director responses from the same BC/BS plan.

[3] When BC/BS plans were first offered in the 1930s, all applicants were accepted for coverage regardless of their health status—i.e., open enrollment. Today, plans in 12 States have an open enrollment period, although most contracts have waiting periods for preexisting conditions.

**Table 2-3—Number of People Insured by OTA Survey Respondents**

| | Commercial insurers | BC/BS plans—underwriters/ medical directors | HMOs |
|---|---|---|---|
| Individual policies | 2.0 million (range: 171 to 240,000) | 1.7 million/1.4 million (range: 1,500 to 690,559)/ (range: 0 to 324,800) | 306,861 (range: 350 to 258,945) |
| Medically underwritten group policies | 2.3 million (range: 1,000 to 382,000) | 2.4 million/671,385 (range: 1,039 to 1,592,000)/ (range: 0 to 205,144) | 4.2 million (range: 1,501 to 2 million) |
| Nongroup/open enrollment | NA | 645,164/134,878 (range: 550 to 512,477)/ (range: 675 to 43,589) | NA |

NA = Not applicable.

SOURCE: Office of Technology Assessment, 1992.

reported their plans received a total of 103,726 individual applications, with a range of 1,200 to 19,000 applications; medical directors reported receiving 101,391 medically underwritten group applications, with a range of 0 to 34,000. Finally, a total of 29,360 applications were received by underwriters during open enrollment, with a range of 60 to 25,000 applications received. Medical directors reported they received 13,768 applications during open enrollment, with a range of 0 to 6,168.

Underwriters for BC/BS plans responding to the OTA survey reported that their plans insure 1,736,270 people through individual policies, 2,394,703 in medically underwritten groups, and 645,164 under open enrollment contracts. Medical directors at BC/BS plans responding to the OTA survey said their plans insure 1,383,166 through individual policies, 671,385 in medically underwritten groups, and 134,878 under open enrollment contracts.

Based on the survey responses of chief underwriters, the fraction of persons covered through self-funded policies ranged from 1 to 62 percent, with an average of 23 percent. One to 49 percent of BC/BS clients were covered by individual policies, with an average of 14 percent. The percentage of persons covered under medically underwritten group policies ranged from 4 to 73 percent, and averaged 20 percent. Finally, underwriters from BC/BS plans responding to the OTA survey covered 19 to 82 percent of people under large group policies, with an average of 44 percent.

For BC/BS medical directors who responded to the OTA survey, a range of 0 to 66 percent of clients were covered under self-funded policies, with an average of 24 percent. One to 49 percent of persons were covered under individual policies, with an average of 15 percent. Coverage under medically underwritten group policies for this survey population ranged from 4 to 60 percent, with an average of 14 percent. Clients covered under large group policies also varied widely, ranging from 10 to 73 percent, with an average of 46 percent.

### *Health Maintenance Organizations*

As of December 1990, there were 569 HMOs in the United States. OTA sent surveys to the 50 largest HMOs, as well as a sample of 28 plans that were the largest HMOs within a State or the largest by HMO model type. (Four HMO types exist: the staff plan, group plan, network plan, and the individual practice association plan.) Forty-three surveys were returned, of which 20 neither offered individual policies nor medically underwrite groups. Of the 23 HMOs responding that do offer such coverage, 11 HMOs accept individuals and 20 medically underwrite groups (table 2-1). Eighteen of the 23 HMOs responding are federally qualified plans. Of the 23 respondents, 1 wrote disability policies, and 4 wrote life insurance.

As a group, responding HMOs received 69,554 applications for individual coverage in 1990, with a range of 24 to 43,000; 414,977 applications were received for medically underwritten group coverage, with a range of 150 to 350,000. Survey respondents covered a total of 306,861 individual members, with membership ranging from 350 to 258,945. Those HMOs that offer medically underwritten group policies cover about 4.2 million people under such policies, with a range of 1,501 to 2 million people.

The percentage of persons within each HMO covered under self-funded policies ranged from 0 to 61 percent, with an average of about 4 percent (20 of the responding 43 HMOs had no self-funded policies). Zero to 34 percent of persons were covered through individual policies, with an average of 3 percent (11 HMOs had no individual policies). The percentage of persons covered under medically underwritten group policies ranged from 0 to 100 percent, and averaged 68 percent. Finally, HMOs responding to the OTA survey covered 0 to 99 percent of their clients under large group policies, with an average of 25 percent.

## TREATMENT OF APPLICATIONS

The outcome of underwriting is risk classification, the final evaluation of whether the applicant for insurance will be covered on a standard or substandard basis, or not at all. Not all insurers view specific conditions the same. A medical condition or impairment that makes an applicant uninsurable to one insurer could be excluded from coverage by another, be included in a policy at a rated (higher-priced) premium, or be ignored altogether. This section describes data related to the treatment of applications for existing clientele. Chapter 3 describes data on how respondents *would* treat applications under specific scenarios.

### *Commercial Health Insurers*

Most applicants for individual health insurance are classified as standard and can purchase coverage without additional premiums or limitations (i.e., exclusions). Over half (18 of 29) of commercial insurers responding to the OTA survey provided standard coverage to at least 60 percent of their individual applicants. Three-quarters of the respondents (30 of 38) underwriting small groups also cover 60 to 100 percent of group members on a standard basis.

Substandard policies can include an exclusion waiver, a rated premium, or both. Exclusion waivers temporarily or permanently exclude a medical condition from coverage. The exclusion may be for a specific condition, such as gallstones, or for an entire organ system, such as reproductive disorders. More than half (18 of 29) of responding commercial insurers reported that 0 to 19 percent of their individual policies carried an exclusion waiver. (Information on the duration of the waiver was not gathered in this survey.) Four companies imposed exclusions for 20 to 34 percent of their individual coverage applicants. Thirty-three of 38 commercial respondents that offer medically underwritten group coverage required exclusion waivers for 0 to 20 percent of applicants.

Sixteen of 29 commercial insurers that offer individual coverage reported that the increased risk associated with 1 to 20 percent of their applicants required a rated premium. The cost of additional premiums usually ranges from 25 to 100 percent of the standard premium, although some insurers use higher ratings (1). In this survey, OTA found that 18 commercial companies that offer medically underwritten group coverage never charge applicants a rated (higher priced) premium.

All 39 companies that offer individual policies declined some portion of applicants; responses ranged from 2 to 22 percent of applicants. Similarly, all 27 companies offering medically underwritten group coverage declined between 1 and 30 percent of applicants for these policies.

### *Blue Cross and Blue Shield Plans*

Although BC/BS plans generally do not screen for high-risk applicants as exhaustively as do commercial carriers, the risk classification that is used once a high-risk applicant is identified varies little from the approach used by commercial carriers (3). A majority of BC/BS plans represented by the underwriter survey (17 of 25) do not offer standard coverage for their individual applicants; 7 BC/BS plans reported offering standard rates for 25 to 85 percent of individual applicants. About half (11 of 21) of BC/BS plans offering medically underwritten group coverage do not offer standard rates to any applicants. Seven respondents offer standard rates to 10 to 25 percent of applicants for medically underwritten group coverage.

For BC/BS plans represented by a medical director survey, 10 of 18 plans that offer individual coverage do not offer standard coverage to any applicants. Five of the 18 plans that offer individual coverage did so at standard rates to 60 percent or more of all applicants. For medically underwritten groups, one-third (5 of 15) of plans do not offer standard coverage to any applicants. Four of 15 BC/BS plans represented by a medical director survey that offer medically underwritten group coverage offered standard rates to less than 30 percent of applicants. Another four BC/BS plans

offered standard rates to more than 75 percent of applicants.

BC/BS plans generally do not offer coverage at standard rates to open enrollment applicants; seven of eight BC/BS underwriters that work for plans with open enrollment reported that applicants for this type of coverage are not offered standard rates. Three of seven BC/BS medical directors that work for plans with open enrollment said they do not offer individual coverage to any applicants at standard rates. Most plans attempt to hold down premium rates for open enrollment subscribers by providing less comprehensive benefits relative to medically underwritten applicants. Others require open enrollment subscribers to pay higher premiums than underwritten applicants for identical coverage. Open enrollment coverage of high-risk applicants usually entails waiting periods before initial benefits may be paid and may impose limitations on coverage of preexisting conditions (3).

The majority of BC/BS plans represented by underwriter surveys (23 of 25) offering individual coverage do so with standard rates, but with exclusion waivers for 0 to 50 percent of applicants. However, of the 21 plans offering medically underwritten group coverage, over half (14 plans) do not offer coverage at standard rates with an exclusion waiver to any applicants. The remaining five responding plans offered this coverage to less than 10 percent of applicants. None of the eight BC/BS underwriters' plans offered open enrollment coverage at standard rates with an exclusion waiver.

Eight of 18 BC/BS plan medical directors said their plans do not offer standard coverage with an exclusion waiver to anyone applying for individual coverage; the remaining eight BC/BS plans offer standard coverage with an exclusion waiver to less than 27 percent of applicants for individual coverage. Eight of 15 medical directors of BC/BS plans that offer medically underwritten group policies said they do not offer standard coverage with an exclusion waiver to any applicants; the remaining seven BC/BS plans offer this type of coverage to less than 11 percent of all medically underwritten group applicants. For open enrollment, a majority (5 of 7) of medical directors from BC/BS plans that offer such coverage said they offer standard rates with an exclusion waiver to any open enrollment applicant.

Underwriters from 15 of the 25 BC/BS plans offering individual policies responded that more than 50 percent of their applicants are offered coverage at a standard premium but with a waiting period, as do 13 of 21 BC/BS plans offering medically underwritten group coverage. Underwriters at four of eight BC/BS plans offering open enrollment said their plans offer applicants standard rates, but require waiting periods.

Medical directors from 11 of the 18 BC/BS plans that write individual coverage said more than 58 percent of their plans' applicants are offered policies at a standard premium but with a waiting period. Six of 18 BC/BS plans do not offer standard rates with a waiting period to any medically underwritten group applicants, but medical directors from six other BC/BS plans reported their plans offer such coverage to more than 65 percent of their applicants. Three of 7 BC/BS plans offering open enrollment do not give standard rates with a waiting period to any applicants, while two of seven give this coverage to all applicants.

Requiring a rated premium with no waiting period or exclusion waiver was uncommon for plans offering individual coverage—only one plan covered applicants this way among surveys returned by chief underwriters. Although a majority of chief underwriters at BC/BS plans that medically underwrite groups (12 of 21) reported they never offered applicants a rated premium with no waiting period or exclusion waiver, a few plans did: 6 did less than 50 percent of the time and 2 did for more than 80 percent of their applicants. However, no plans offering open enrollment covered applicants this way.

No medical directors from the 18 BC/BS plans that write individual policies offered such coverage at a rated premium without a waiting period or exclusion waiver. Similarly, medical directors from 11 of 15 BC/BS plans said they never offered medically underwritten group coverage with a rated premium and no waiting period or exclusion waiver. A majority (5 of 7) of medical directors from BC/BS plans offering open enrollment said they did not offer this type of coverage to any applicant.

Only 1 of the 25 underwriters from BC/BS plans offering individual coverage responded he or she did so with a rated premium and an exclusion waiver—to 1 percent of applicants. Underwriters from 22 of 25 BC/BS plans offering individual coverage said their plans did not cover any applicants with a waiting period and a rated premium. Six BC/BS

plans offering medically underwritten group policies covered less than 25 percent of applicants with a waiting period and a rated premium, but 13 plans represented by underwriters never offered this coverage. No open enrollment plans offered coverage with a waiting period or an exclusion waiver and a rated premium.

None of the medical directors from BC/BS plans that offer individual policies said their plan covered any applicants with a rated premium and an exclusion waiver. Medical directors from 12 of 15 BC/BS plans that offer medically underwritten group policies said their plans do not cover any applicants with a rated premium and an exclusion waiver. Fifteen of 18 medical directors from BC/BS plans that offer individual coverage said their plans do not cover any applicants with a waiting period and a rated premium. Medical directors from 10 of the 15 BC/BS plans that offer medically underwritten group coverage said their plans do not cover any applicants with a waiting period and a rated premium.

For BC/BS plans represented by the underwriter population, 19 of 21 plans that offer individual coverage declined applicants between 0 and 25 percent of the time. Nearly all responding underwriters from BC/BS plans (20 of 21) said they declined applicants less than 35 percent of the time. Medical directors from 15 of the 18 BC/BS plans that offer individual coverage reported their plans declined applicants between 0 and 25 percent of the time. Thirteen of the 15 BC/BS plans returned by a medical director declined applicants for medically underwritten group coverage less than 3 percent of the time.

### *Health Maintenance Organizations*

All 11 HMOs offering individual coverage accept more than 50 percent of their applicants at standard rates. Three-quarters (16 of 20 respondents) of those HMOs offering medically underwritten group coverage offer standard rates to more than 50 percent of their applicants. The majority of HMOs offering individual coverage (9 of 11) do not use exclusion waivers, and a similar proportion of HMOs offering medically underwritten group coverage (15 of 20) also do not use exclusion waivers. Similar proportions were found for HMOs covering applicants with rated premiums: 10 of the 11 HMOs offering individual coverage and 13 of the 20 offering medically underwritten coverage never provide coverage with a rated premium.

Clearly, HMO practices are either to accept applicants or to decline them. Rarely did HMO survey respondents report accepting an applicant with a restriction on the policy. More than half of responding HMOs that offer individual coverage (6 of 11) declined applicants less than 25 percent of the time. The remaining 5 respondents declined applicants for coverage less than 45 percent of the time. For HMOs offering medically underwritten group coverage, the proportion of declined applicants was similar: 15 of the 20 offering medically underwritten group coverage declined coverage less than 25 percent of the time.

## CHAPTER 2 REFERENCES

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3. U.S. Congress, Office of Technology Assessment, *Medical Testing and Health Insurance*, OTA-H-384 (Washington, DC: U.S. Government Printing Office, August 1988).
4. U.S. Congress, Office of Technology Assessment, *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening*, OTA-BA-532 (Washington, DC: U.S. Government Printing Office, August 1992)

An underwriter's objective is to know as much about the applicant's health status as the applicant. Any health insurance policy based on medical underwriting requires the applicant (and each family member for family policies) to complete a health history questionnaire and to release medical records. In some cases, insurers might also require physical examinations or laboratory tests.

## UNDERWRITING PRACTICES

For commercial health insurers offering individual coverage, the majority (23 of 29) surveyed by OTA required a personal health history of all applicants. The same is true for commercial companies offering medically underwritten coverage: 29 of 37 required one of all applicants.

For Blue Cross and Blue Shield (BC/BS) plans represented by the underwriter survey, 22 of 25 plans offering individual coverage required a personal health history of all applicants; 17 of 21 plans offering medically underwritten group coverage required one of all applicants. Underwriters at six of the eight BC/BS plans with open enrollment coverage said their plans did not require a personal history from any applicants. Sixteen of 18 BC/BS plans represented by a medical director survey required a personal health history of all applicants. Thirteen of 15 BC/BS plans represented by a medical director survey required one of all applicants as well. Of those BC/BS plans from medical directors that had open enrollment, 4 of 6 did not require a personal health history from any applicants. For health maintenance organizations (HMOs), 7 of 11 plans offering individual coverage required a personal health history of all applicants. Nine of 20 HMOs required one of all medically underwritten group applicants; all of the remaining plans required a personal health history for less than 40 percent of their applicants.

Family health histories were required of all individual applicants for 14 of 29 commercial insurers; 12 individual insurers did not require one of any applicants. For commercial insurers offering medically underwritten group coverage, nearly half (16 of 37) did not require a family history from any applicants, while 12 required one from all applicants. A majority of BC/BS plans (20 of 25) represented by an underwriter survey never required a family history of individual applicants or medically underwritten group applicants (19 of 21), or open enrollment applicants (7 of 8). Sixteen of 18 BC/BS plans represented by medical directors did not require a family history of any individual applicants. Fourteen of 15 BC/BS plans represented by the underwriter population did not require one from any medically underwritten group applicants. The same holds true for HMOs, with 9 of 11 that offer individual coverage not requiring a family history of any applicants and 14 of 20 never requiring one of medically underwritten group applicants.

Of those commercial insurers requiring a family health history, six routinely request information about the applicant's parents, and five respondents request information about an applicant's spouse and children. Of the few BC/BS plans represented by an underwriter survey that required a family history, information on an applicant's spouse and children is most often requested. Four required information about a spouse and five seek information about children. Health histories on spouse (2 plans) and children (2 plans) are the only ones used by BC/BS plans represented by medical directors. Finally, for HMOs using a family history, information is obtained most often on an applicant's spouse (6 plans) and children (6 plans).

Varying widely are company procedures pertaining to the proportion of applicants required to provide further evidence of their health status through an attending physician statement (APS), physical examination, or blood/urine test. The standard APS form calls for a complete description of a patient's complaints, any abnormal findings (including laboratory and other test results), treatment or operations, present condition, if known, and other medical information with a bearing on an applicant's health, such as smoking or alcohol use. For children under 6 months of age, additional information might be sought regarding birth weight and the presence of any disease or abnormality (2).

For both medically underwritten groups and individual policies, the APS is the most common



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supplemental source of information for underwriting beyond the health data provided directly through the insurance application (2). For individual applicants, a quarter of commercial insurers (10 of 39) required an APS for less than 25 percent of applicants, 12 required one for between 25 and 50 percent of applicants, and 9 for over 50 percent of applicants. Twenty-four commercial plans required an APS for less than 25 percent of medically underwritten group applicants.

Overall, close to half (12 of 25) of underwriters from BC/BS plans offering individual coverage required an APS for less than 25 percent of applicants; 13 of 21 offering medically underwritten coverage required an APS for less than 25 percent of applicants. Underwriters from seven of the eight BC/BS open enrollment plans said they never required an APS of applicants. Eight of 18 BC/BS plans for the medical director population required an APS for 25 to 50 percent of individual applicants, seven required one from less than 25 percent of applicants. Medical directors from all 15 BC/BS plans that offer medically underwritten group coverage said they required an APS for less than 50 percent of applicants. Over half the HMOs (6 of 11) that offer individual coverage required an APS for 50 to 75 percent of applicants, while four required one for less than 20 percent of applicants. Fifty percent (10 of 20) of HMOs did not require an APS for any medically underwritten group applicants, 8 required them for less than 10 percent of applicants.

For commercial companies, an APS was triggered most often by reports of any significant (39 companies) or selected (31 companies) diagnosis or symptoms on the application, or because of a Medical Information Bureau, Inc. (MIB) report (26 companies). Applications for individual insurance—health, life, or disability—carry an explanation about MIB. MIB's reports alert a potential insurer to omissions or misrepresentation of facts by an applicant (3). In the BC/BS underwriter/medical director surveys, any significant (19 plans/11 plans) or selected (16 plans/10 plans) diagnosis or symptoms reported on the application triggered an APS. Twelve HMOs required an APS because of any significant diagnosis or symptoms in the application, and 11 HMOs required one because of selected diagnoses or symptoms.

Physical examinations of individual health insurance applicants are much less common than other underwriting practices. Five of 29 commercial insurers did not require physical exams of any individual applicants, 22 required a physical exam of less than 40 percent of applicants. Thirty-four of 37 companies required a physical exam from less than 25 percent of medically underwritten group applicants.

Seventeen of 25 BC/BS plans represented by the medical director population did not require a physical exam of any individual applicants. Physical exams are not required of any medically underwritten group applicants in 16 of 21 BC/BS plans. Medical directors at 10 of 18 BC/BS plans that offer individual coverage said their plans did not require a physical exam of any applicants. The remaining plans required them of less than 20 percent of applicants. Of the 15 BC/BS plans represented by the medical director population, 12 do not require a physical exam of any medically underwritten group applicants. For the 11 HMOs that write individual policies, physical exams are required for less than 30 percent of applicants. Only one of 20 HMOs requires a physical exam for medically underwritten group coverage.

If commercial insurers require a physical exam, it is usually triggered because of selected diagnoses or symptoms reported on an application (21 plans), or an MIB report (22 plans). Underwriters at six BC/BS plans reported that selected diagnoses or symptoms in the application, and any significant diagnosis or symptoms in the APS, can trigger a physical exam. Four BC/BS plans represented by the medical director population said that any significant diagnosis or symptoms in the APS prompts a physical exam, as they can for four HMOs.

Insurers generally use the standard blood tests and urinalysis that are commonly ordered by physicians as part of a general physical evaluation. Such panels can detect indicators of use of illicit drugs, as well as nicotine and prescription medications for diabetes, heart disease, and hypertension. The insurer's interest in prescription medicine is twofold; first, to identify applicants who are not forthcoming in their health history questionnaire and, second, to determine whether known hypertensive applicants, for example, are conscientiously following prescribed treatment (2).

Twenty of 29 commercial companies required blood or urine screens of less than 30 percent of individual applicants; 33 of 37 commercial compa-

nies required blood or urine screens of less than 30 percent of medically underwritten group applicants. Eleven commercial companies did not require them of any medically underwritten group applicants. Blood or urine screens are not required of individual applicants by underwriters at 20 of 25 BC/BS plans. Nineteen of 21 BC/BS plans represented by an underwriter survey did not require blood or urine screens of any medically underwritten group applicants. Medical directors from 15 of 18 BC/BS plans said they did not require blood or urine screens from any individual applicants; all 15 plans that offer medically underwritten group coverage never required a blood or urine screen. Nine of the 11 HMOs that offer individual coverage said blood or urine screens are required of less than 20 percent of applicants. Nineteen of 20 HMOs never required them of any medically underwritten group applicants.

## FACTORS IN INSURABILITY

Insurability is not just a matter of health status; several factors are involved in an underwriter's decision to accept or deny an application, to exclude coverage for a condition, or to charge a higher premium. When asked to indicate which nonmedical underwriting factors could affect acceptance of an individual application, commercial insurers most commonly cited smoking habits, age, and occupation. For medically underwritten group applicants, insurers cited age, occupation, and sex (table 3-1).

An individual applicant's smoking status is considered "important" or "very important" by 24 of 29 commercial insurers. Twenty-three of 29 commercial insurers offering individual insurance said age was important or very important. An applicant's occupation is important or very important to 21 (41 percent) insurers of individuals. Eighteen (35 percent) commercial insurers of group applicants consider age, occupation, and gender to be important factors in determining insurability.

Personal and family medial histories were the most important factors in determining insurability for respondents regardless of whether they were from a commercial insurer, HMO, or BC/BS plan. For commercial insurers, for example, all individual and group insurers thought a personal history of significant conditions was very important. However, only 16 of 29 individual insurers and 17 of 37 commercial group insurers thought a family medical history was important. Insurers of both individuals and groups found genetic predispositions as well as carrier risk for genetic diseases to be relatively unimportant. Genetic predisposition was a very important criterion to 4 of 29 commercial insurers that offer individual policies, important to 6, unimportant to 3, and never used by 16. Eighteen of 37 group insurers found genetic predispositions to be important, with an equal number never using it in determining insurability. Carrier risk for genetic disease was considered important in determining insurability by 7 of 29 companies that insured individuals and by 10 of 37 group insurers. Similar results were obtained for BC/BS plans and HMOs (table 3-1).

### *Information on Specific Conditions*

When certain conditions are detected either in an examination or an application, how do they affect the rating of applicants by insurers? The majority of commercial insurers would not accept individual applicants with standard rates for any of the conditions listed in the OTA survey (table 3-2). A large proportion would decline the applicant. Fewer applicants with hypertension were declined than those who had cerebrovascular disease, diabetes, or cystic fibrosis (CF). HMOs generally accepted individual applicants with the listed conditions, but often with an exclusion waiver and a rated premium. Eight of 11 HMOs that offer individual coverage declined individual applicants with hemophilia and CF (table 3-2). Individual applicants with the listed conditions were most often declined coverage from BC/BS plans (table 3-3). Those applicants with hypertension were declined least often, while applicants with hemophilia and sickle cell anemia were declined most often.

Commercial insurers declined to cover the majority of medically underwritten groups with members who had one of the conditions in table 3-2, except for groups with applicants who had hypertension. In fact, medically underwritten groups with appliants who had hypertension were frequently accepted with standard rates by commercial insurers, BC/BS plans, and HMOs (tables 3-2 and 3-3). When medically underwritten group policies were accepted with applicants having one of the other conditions listed in the OTA survey, most BC/BS plans required either a rated premium or a waiting period (table 3-3), and again, applicants were most often declined

**Table 3-1—Factors in Determining Insurability**

Question: For each category of coverage, please indicate the importance of each of the following factors in determining insurability (not in rating):

| | Respondent | Very important | Important | Unimportant | Never used | No response[a] |
|---|---|---|---|---|---|---|
| Individual policies | | | | | | |
| Age | *Commercials* | 11 (38%) | 12 (41%) | 5 (17%) | 1 ( 3%) | 0 ( 0%) |
| | *HMOs* | 0 ( 0%) | 3 (27%) | 7 (64%) | 1 ( 9%) | 1 ( 9%) |
| | *BC/BS plans-U*[b] | 0 ( 0%) | 9 (36%) | 7 (28%) | 8 (32%) | 1 ( 4%) |
| | *BC/BS plans-M* | 3 (17%) | 6 (33%) | 4 (22%) | 5 (28%) | 0 ( 0%) |
| Occupation | *Commercials* | 3 (10%) | 18 (62%) | 7 (24%) | 1 ( 3%) | 0 ( 0%) |
| | *HMOs* | 0 ( 0%) | 2 (18%) | 3 (27%) | 5 (45%) | 1 ( 9%) |
| | *BC/BS plans-U* | 0 ( 0%) | 3 (12%) | 10 (40%) | 11 (44%) | 1 ( 4%) |
| | *BC/BS plans-M* | 0 ( 0%) | 6 (33%) | 3 (17%) | 9 (50%) | 0 ( 0%) |
| Smoking status | *Commercials* | 9 (31%) | 15 (52%) | 2 (71%) | 3 (10%) | 0 ( 0%) |
| | *HMOs* | 1 ( 9%) | 5 (45%) | 1 ( 9%) | 3 (27%) | 1 ( 9%) |
| | *BC/BS plans-U* | 3 (12%) | 9 (36%) | 4 (16%) | 8 (32%) | 1 ( 4%) |
| | *BC/BS plans-M* | 3 (17%) | 5 (28%) | 1 ( 6%) | 9 (50%) | 0 ( 0%) |
| Lifestyle | *Commercials* | 1 ( 3%) | 10 (34%) | 3 (10%) | 14 (48%) | 1 ( 3%) |
| | *HMOs* | 0 ( 0%) | 3 (27%) | 2 (18%) | 5 (45%) | 1 ( 9%) |
| | *BC/BS plans-U* | 1 ( 4%) | 5 (20%) | 6 (24%) | 12 (48%) | 1 ( 4%) |
| | *BC/BS plans-M* | 1 ( 6%) | 5 (28%) | 1 ( 6%) | 11 (61%) | 0 ( 0%) |
| Sex | *Commercials* | 5 (17%) | 4 (14%) | 7 (24%) | 13 (45%) | 0 ( 0%) |
| | *HMOs* | 0 ( 0%) | 0 ( 0%) | 2 (18%) | 8 (73%) | 1 ( 9%) |
| | *BC/BS plans-U* | 0 ( 0%) | 3 (12%) | 7 (28%) | 14 (56%) | 1 ( 4%) |
| | *BC/BS plans-M* | 1 ( 6%) | 5 (28%) | 3 (17%) | 9 (50%) | 0 ( 0%) |
| Financial/credit status | *Commercials* | 2 ( 7%) | 11 (38%) | 9 (31%) | 7 (24%) | 0 ( 0%) |
| | *HMOs* | 0 ( 0%) | 0 ( 0%) | 3 (27%) | 7 (64%) | 1 ( 9%) |
| | *BC/BS plans-U* | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 24 (96%) | 1 ( 4%) |
| | *BC/BS plans-M* | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 18 (100%) | 0 ( 0%) |
| Personal medical history of significant conditions | *Commercials* | 29(100%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) |
| | *HMOs* | 9 (82%) | 0 ( 0%) | 0 ( 0%) | 1 ( 9%) | 1 ( 9%) |
| | *BC/BS plans-U* | 22 (88%) | 1 ( 4%) | 0 ( 0%) | 1 ( 4%) | 1 ( 4%) |
| | *BC/BS plans-M* | 16 (89%) | 0 ( 0%) | 0 ( 0%) | 2 (11%) | 0 ( 0%) |
| Family medical history of significant conditions | *Commercials* | 5 (17%) | 11 (38%) | 9 (31%) | 4 (14%) | 0 ( 0%) |
| | *HMOs* | 1 ( 9%) | 0 ( 0%) | 2 (18%) | 7 (64%) | 1 ( 9%) |
| | *BC/BS plans-U* | 0 ( 0%) | 6 (24%) | 4 (16%) | 14 (56%) | 1 ( 4%) |
| | *BC/BS plans-M* | 0 ( 0%) | 4 (22%) | 4 (22%) | 10 (56%) | 0 ( 0%) |
| Genetic predisposition to significant conditions | *Commercials* | 4 (14%) | 6 (21%) | 3 (10%) | 16 (55%) | 0 ( 0%) |
| | *HMOs* | 0 ( 0%) | 3 (27%) | 1 (18%) | 6 (55%) | 1 ( 9%) |
| | *BC/BS plans-U* | 1 ( 4%) | 2 ( 8%) | 5 (20%) | 16 (64%) | 1 ( 4%) |
| | *BC/BS plans-M* | 0 ( 0%) | 3 (17%) | 1 ( 6%) | 14 (78%) | 0 ( 0%) |
| Carrier risk for genetic disease | *Commercials* | 2 ( 7%) | 5 (17%) | 6 (21%) | 16 (55%) | 0 ( 0%) |
| | *HMOs* | 0 ( 0%) | 2 (18%) | 1 (18%) | 7 (64%) | 1 ( 9%) |
| | *BC/BS plans-U* | 0 ( 0%) | 2 ( 8%) | 5 (20%) | 17 (68%) | 1 ( 4%) |
| | *BC/BS plans-M* | 0 ( 0%) | 3 (17%) | 1 ( 6%) | 14 (78%) | 0 ( 0%) |

for coverage by BC/BS plans when they had cerebrovascular disease, hemophilia, or sickle cell anemia.

### *Inquiries About Genetic Conditions*

Do applications for either individual or medically underwritten group insurance coverage contain questions about genetic conditions? OTA asked insurers whether questions on genetic conditions were included in either a personal history, a family history, or neither. For individual policies, the majority of commercial insurers did not inquire about any of the listed genetic conditions in either the personal or family history (table 3-4). Five of 29 commercial

**Table 3-1—Factors in Determining Insurability—Continued**

Question: For each category of coverage, please indicate the importance of each of the following factors in determining insurability (not in rating):

| | Respondent | Very important | Important | Unimportant | Never used | No response[a] |
|---|---|---|---|---|---|---|
| **Medically underwritten group policies** | | | | | | |
| Age | *Commercials* | 4 (11%) | 14 (38%) | 11 (30%) | 8 (22%) | 0 ( 0%) |
| | *HMOs* | 3 (15%) | 6 (30%) | 0 ( 0%) | 10 (50%) | 1 ( 5%) |
| | *BC/BS plans-U*[b] | 1 ( 5%) | 9 (43%) | 4 (19%) | 7 (33%) | 0 ( 0%) |
| | *BC/BS plans-M* | 3 (20%) | 5 (33%) | 4 (27%) | 3 (20%) | 0 ( 0%) |
| Occupation | *Commercials* | 4 (11%) | 14 (38%) | 12 (32%) | 7 (19%) | 0 ( 0%) |
| | *HMOs* | 4 (20%) | 6 (30%) | 4 (20%) | 5 (25%) | 1 ( 5%) |
| | *BC/BS plans-U* | 1 ( 5%) | 7 (33%) | 5 (24%) | 8 (38%) | 0 ( 0%) |
| | *BC/BS plans-M* | 1 ( 6%) | 9 (60%) | 1 ( 6%) | 4 (28%) | 0 ( 0%) |
| Smoking status | *Commercials* | 2 ( 5%) | 14 (38%) | 10 (27%) | 11 (30%) | 0 ( 0%) |
| | *HMOs* | 2 (10%) | 4 (20%) | 2 (10%) | 11 (55%) | 1 ( 5%) |
| | *BC/BS plans-U* | 1 ( 5%) | 7 (33%) | 5 (24%) | 8 (38%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 4 (27%) | 2 (13%) | 9 (60%) | 0 ( 0%) |
| Lifestyle | *Commercials* | 1 ( 3%) | 7 (19%) | 7 (19%) | 20 (54%) | 2 ( 5%) |
| | *HMOs* | 1 ( 5%) | 6 (30%) | 2 (10%) | 10 (50%) | 1 ( 5%) |
| | *BC/BS plans-U* | 1 ( 5%) | 6 (29%) | 3 (14%) | 12 (57%) | 0 ( 0%) |
| | *BC/BS plans-M* | 1 ( 6%) | 4 (27%) | 3 (20%) | 7 (47%) | 0 ( 0%) |
| Sex | *Commercials* | 0 ( 0%) | 6 (16%) | 12 (32%) | 19 (51%) | 0 ( 0%) |
| | *HMOs* | 0 ( 0%) | 5 (25%) | 1 ( 5%) | 13 (65%) | 1 ( 5%) |
| | *BC/BS plans-U* | 1 ( 5%) | 4 (19%) | 5 (24%) | 11 (52%) | 0 ( 0%) |
| | *BC/BS plans-M* | 1 ( 6%) | 6 (40%) | 3 (20%) | 5 (33%) | 0 ( 0%) |
| Financial/credit status | *Commercials* | 1 ( 3%) | 4 (11%) | 11 (30%) | 20 (54%) | 1 ( 3%) |
| | *HMOs* | 3 (15%) | 3 (15%) | 1 ( 5%) | 12 (65%) | 1 ( 5%) |
| | *BC/BS plans-U* | 1 ( 5%) | 3 (14%) | 1 ( 5%) | 16 (76%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 1 ( 6%) | 1 ( 6%) | 13 (87%) | 0 ( 0%) |
| Personal medical history of significant conditions | *Commercials* | 36 (95%) | 1 ( 3%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) |
| | *HMOs* | 15 (75%) | 1 ( 5%) | 0 ( 0%) | 3 (15%) | 1 ( 5%) |
| | *BC/BS plans-U* | 18 (86%) | 1 ( 5%) | 0 ( 0%) | 2 (10%) | 0 ( 0%) |
| | *BC/BS plans-M* | 15 (100%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) |
| Family medical history of significant conditions | *Commercials* | 3 ( 8%) | 14 (37%) | 10 (27%) | 9 (24%) | 1 ( 3%) |
| | *HMOs* | 4 (20%) | 3 (15%) | 2 (10%) | 10 (50%) | 1 ( 5%) |
| | *BC/BS plans-U* | 1 ( 5%) | 3 (14%) | 4 (19%) | 13 (62%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 4 (27%) | 3 (20%) | 8 (53%) | 0 ( 0%) |
| Genetic predisposition to significant conditions | *Commercials* | 0 ( 0%) | 12 (32%) | 6 (16%) | 18 (49%) | 1 ( 3%) |
| | *HMOs* | 0 ( 0%) | 3 (15%) | 2 (10%) | 13 (65%) | 2 (10%) |
| | *BC/BS plans-U* | 1 ( 5%) | 1 ( 5%) | 4 (19%) | 15 (71%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 3 (20%) | 1 ( 7%) | 11 (63%) | 0 ( 0%) |
| Carrier risk for genetic disease | *Commercials* | 1 ( 3%) | 9 (24%) | 9 (24%) | 17 (46%) | 1 ( 3%) |
| | *HMOs* | 0 ( 0%) | 3 (15%) | 2 (10%) | 13 (65%) | 2 (10%) |
| | *BC/BS plans-U* | 1 ( 5%) | 0 ( 0%) | 5 (24%) | 15 (71%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 3 (20%) | 2 (13%) | 10 (67%) | 0 ( 0%) |

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

insurers that offer individual coverage inquired about Tay-Sachs, Huntington disease, sickle cell anemia, and CF in the personal history; 7 insurers inquired about hemophilia in the personal history. However, genetic conditions were of greater interest to HMOs and BC/BS plans. Inquiries in the personal history about hemophilia were the most common.

More than half of commercial insurers (26 of 37) that offer medically underwritten group coverage never inquired about the listed genetic conditions in either the personal or family history. Eight commercial insurers responded that they inquired about all of the genetic conditions in OTA's survey in the personal history. Fewer HMOs and BC/BS plans

**Table 3-2—Treatment of Applicants with Specific Conditions: Commercials and HMOs**

How would you normally treat either an individual policy applicant or medically underwritten groups that disclosed the following conditions in an examination(s) or application:

| | Respondent | Accepted with standard rates | Accepted with exclusion waiver at standard rates | Accepted with exclusion waiver at rated premium | Accepted without exclusion waiver at rated premium | Declined | No response[a] |
|---|---|---|---|---|---|---|---|
| **Individual policies** | | | | | | | |
| Hypertension | *Commercials* | 5 (17%) | 2 (7%) | 2 ( 7%) | 13 (45%) | 0 (0%) | 7 (24%) |
| | *HMOs* | 2 (18%) | 0 (0%) | 2 (18%) | 0 ( 0%) | 1 (9%) | 6 (55%) |
| Diabetes mellitus | *Commercials* | 1 ( 3%) | 0 (0%) | 2 (7%) | 7 (24%) | 15 (52%) | 4 (14%) |
| | *HMOs* | 2 (18%) | 0 (0%) | 1 (9%) | 0 ( 0%) | 2 (18%) | 6 (55%) |
| Cerebrovascular disease | *Commercials* | 0 ( 0%) | 1 (3%) | 0 (0%) | 5 (17%) | 16 (56%) | 7 (24%) |
| | *HMOs* | 1 ( 9%) | 0 (0%) | 0 (0%) | 0 ( 0%) | 6 (55%) | 4 (36%) |
| Hemophilia | *Commercials* | 1 ( 3%) | 0 (0%) | 0 (0%) | 0 (0%) | 26 (90%) | 2 ( 7%) |
| | *HMOs* | 0 ( 0%) | 0 (0%) | 0 (0%) | 0 (0%) | 8 (73%) | 3 (27%) |
| Cystic fibrosis | *Commercials* | 1 ( 3%) | 0 (0%) | 0 (0%) | 0 (0%) | 26 (90%) | 2 ( 7%) |
| | *HMOs* | 0 ( 0%) | 0 (0%) | 0 (0%) | 0 (0%) | 8 (73%) | 3 (27%) |
| Sickle cell anemia | *Commercials* | 1 ( 3%) | 0 (0%) | 0 (0%) | 0 (0%) | 25 (86%) | 3 (10%) |
| | *HMOs* | 0 ( 0%) | 0 (0%) | 0 (0%) | 0 (0%) | 7 (64%) | 4 (36%) |
| **Medically underwritten group policies** | | | | | | | |
| Hypertension | *Commercials* | 14 (38%) | 0 (0%) | 3 (8%) | 7 (19%) | 0 ( 0%) | 13 (35%) |
| | *HMOs* | 11 (55%) | 0 (0%) | 1 (5%) | 1 ( 5%) | 2 (10%) | 5 (25%) |
| Diabetes mellitus | *Commercials* | 1 ( 3%) | 2 (5%) | 1 (3%) | 6 (16%) | 13 (35%) | 14 (38%) |
| | *HMOs* | 6 (30%) | 0 (0%) | 1 (5%) | 2 (10%) | 4 (20%) | 7 (35%) |
| Cerebrovascular disease | *Commercials* | 1 ( 3%) | 0 (0%) | 0 (0%) | 4 (11%) | 21 (57%) | 11 (30%) |
| | *HMOs* | 4 (20%) | 0 (0%) | 1 (5%) | 1 ( 5%) | 7 (35%) | 7 (35%) |
| Hemophilia | *Commercials* | 0 ( 0%) | 1 (3%) | 0 ( 0%) | 2 (5%) | 30 (81%) | 4 (11%) |
| | *HMOs* | 3 (15%) | 0 (0%) | 2 (10%) | 0 (0%) | 10 (50%) | 5 (25%) |
| Cystic fibrosis | *Commercials* | 0 ( 0%) | 1 (3%) | 1 (3%) | 1 ( 3%) | 31 (84%) | 3 ( 8%) |
| | *HMOs* | 2 (10%) | 0 (0%) | 1 (5%) | 2 (10%) | 10 (50%) | 5 (25%) |
| Sickle cell anemia | *Commercials* | 0 ( 0%) | 0 (0%) | 1 (3%) | 2 ( 5%) | 31 (84%) | 3 ( 8%) |
| | *HMOs* | 4 (20%) | 0 (0%) | 1 (5%) | 2 (10%) | 9 (45%) | 4 (20%) |

[a]Percentages may not add to 100 due to rounding.

SOURCE: Office of Technology Assessment, 1992.

that offered medically underwritten group coverage were interested in the genetic conditions than the HMOs and BC/BS plans that offered individual coverage. More than half of all HMOs did not inquire about the listed conditions in either the personal or family history. Similar numbers were found from responding underwriter and medical directors of BC/BS plans (table 3-4).

### *Effect of Genetic Test Results on Insurability*

Do genetic test results have an effect on insurability? When presymptomatic testing reveals the likelihood of a serious, chronic future disease (e.g., Huntington disease) 17 of 29 commercial insurers would decline an individual applicant, while 8 would accept the applicant at standard rates (table 3-5). Fifteen of 37 commercial insurers that cover medically underwritten groups would decline the applicant, however, 10 insurers would accept the group at standard rates (table 3-5).

Underwriters at 11 of 25 BC/BS plans that provide individual coverage said they would decline an applicant if presymptomatic testing revealed a likelihood of disease (e.g., Huntington disease); 6 would accept the applicant at standard rates. The

## Table 3-3—Treatment of Applicants with Specific Conditions: BC/BS plans

How would you normally treat either an individual policy applicant or medically underwritten groups that disclosed the following conditions in an examination(s) or application:

| | Respondent | Accepted with standard rates | Accepted with exclusion waiver at standard rates | Accepted with waiting period at standard rates | Accepted with exclusion waiver at rated premium | Accepted without exclusion waiver or waiting period/ rated premium | Accepted with waiting period at rated premium | Declined | No response[a] |
|---|---|---|---|---|---|---|---|---|---|
| **Individual policies** | | | | | | | | | |
| Hypertension | *BC/BS plans-U*[b] | 4 (16%) | 6 (24%) | 8 (32%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 8%) | 5 (20%) |
| | *BC/BS plans-M* | 3 (17%) | 4 (22%) | 5 (28%) | 0 ( 0%) | 0 ( 0%) | 1 ( 6%) | 2 (11%) | 3 (17%) |
| Diabetes mellitus | *BC/BS plans-U* | 0 ( 0%) | 4 (16%) | 4 (16%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 14 (56%) | 3 (12%) |
| | *BC/BS plans-M* | 0 ( 0%) | 2 (11%) | 2 (11%) | 0 ( 0%) | 0 ( 0%) | 2 (11%) | 9 (50%) | 3 (17%) |
| Cerebrovascular disease | *BC/BS plans-U* | 0 ( 0%) | 5 (20%) | 4 (16%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 16 (64%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 0 ( 0%) | 3 (17%) | 0 ( 0%) | 0 ( 0%) | 1 ( 6%) | 14 (78%) | 0 ( 0%) |
| Hemophilia | *BC/BS plans-U* | 0 ( 0%) | 2 ( 8%) | 2 ( 8%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 21 (84%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 0 ( 0%) | 3 (17%) | 0 ( 0%) | 0 ( 0%) | 1 ( 6%) | 13 (72%) | 1 ( 6%) |
| Sickle cell anemia | *BC/BS plans-U*[c] | 1 ( 4%) | 4 (16%) | 2 ( 8%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 18 (72%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 0 ( 0%) | 3 (17%) | 0 ( 0%) | 0 ( 0%) | 1 ( 6%) | 13 (72%) | 1 ( 6%) |
| **Medically underwritten group policies** | | | | | | | | | |
| Hypertension | *BC/BS plans-U* | 5 (24%) | 1 ( 5%) | 5 (24%) | 0 ( 0%) | 2 (10%) | 1 ( 5%) | 1 ( 5%) | 6 (29%) |
| | *BC/BS plans-M* | 2 (13%) | 0 ( 0%) | 4 (27%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 2 (13%) | 4 (27%) |
| Diabetes mellitus | *BC/BS plans-U* | 1 ( 5%) | 0 ( 0%) | 3 (14%) | 0 ( 0%) | 1 ( 5%) | 4 (19%) | 8 (38%) | 4 (19%) |
| | *BC/BS plans-M* | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 3 (20%) | 2 (13%) | 6 (40%) | 4 (27%) |
| Cerebrovascular disease | *BC/BS plans-U* | 1 ( 5%) | 1 ( 5%) | 2 (10%) | 0 ( 0%) | 0 ( 0%) | 2 (10%) | 13 (62%) | 2 ( 5%) |
| | *BC/BS plans-M* | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) | 12 (80%) | 0 ( 0%) |
| Hemophilia | *BC/BS plans-U* | 1 ( 5%) | 0 ( 0%) | 1 ( 5%) | 0 ( 0%) | 0 ( 0%) | 2 (10%) | 17 (80%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 7%) | 1 ( 7%) | 12 (88%) | 1 ( 7%) |
| Sickle cell anemia | *BC/BS plans-U* | 1 ( 5%) | 0 ( 0%) | 1 ( 5%) | 1 ( 5%) | 1 ( 5%) | 2 (10%) | 15 (70%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 7%) | 1 ( 7%) | 12 (80%) | 1 ( 7%) |

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.
[c]Due to an editing error, "cystic fibrosis" was inadvertently dropped from the survey instrument that was mailed to the BC/BS populations.

SOURCE: Office of Technology Assessment, 1992.

**Table 3-4—Inquiries About Genetic Conditions**

| Question | Respondent | Personal history | Family history | Neither | No response[a] |
|---|---|---|---|---|---|
| **Does your company specifically inquire, for each category of coverage, about the following conditions in the application for health insurance in the personal history, family history, or neither:** | | | | | |
| **Individual policies** | | | | | |
| Hemophilia | *Commercials* | 7 (24%) | 0 ( 0%) | 21 (73%) | 1 (3%) |
| | *HMOs* | 6 (55%) | 0 ( 0%) | 4 (36%) | 1 (9%) |
| | *BC/BS plans-U*[b] | 14 (56%) | 0 ( 0%) | 9 (36%) | 2 (8%) |
| | *BC/BS plans-M* | 7 (39%) | 0 ( 0%) | 11 (61%) | 0 (0%) |
| Tay-Sachs | *Commercials* | 5 (17%) | 0 ( 0%) | 23 (79%) | 1 (3%) |
| | *HMOs* | 4 (36%) | 2 ( 9%) | 5 (46%) | 1 (9%) |
| | *BC/BS plans-U* | 10 (40%) | 0 ( 0%) | 13 (52%) | 2 (8%) |
| | *BC/BS plans-M* | 8 (44%) | 0 ( 0%) | 10 (56%) | 0 (0%) |
| Huntington disease | *Commercials* | 5 (17%) | 0 ( 0%) | 23 (79%) | 1 (3%) |
| | *HMOs* | 4 (36%) | 1 ( 9%) | 5 (46%) | 1 (9%) |
| | *BC/BS plans-U* | 10 (40%) | 0 ( 0%) | 13 (52%) | 2 (8%) |
| | *BC/BS plans-M* | 7 (39%) | 0 ( 0%) | 11 (61%) | 0 (0%) |
| Sickle cell anemia | *Commercials* | 5 (17%) | 0 ( 0%) | 23 (79%) | 1 (3%) |
| | *HMOs* | 5 (46%) | 1 ( 9%) | 4 (36%) | 1 (9%) |
| | *BC/BS plans-U* | 12 (48%) | 0 ( 0%) | 12 (48%) | 1 (4%) |
| | *BC/BS plans-M* | 8 (44%) | 0 ( 0%) | 10 (56%) | 0 (0%) |
| Cystic fibrosis | *Commercials* | 5 (17%) | 0 ( 0%) | 23 (79%) | 1 (3%) |
| | *HMOs* | 5 (46%) | 1 ( 9%) | 4 (36%) | 1 (9%) |
| | *BC/BS plans-U* | 13 (52%) | 0 ( 0%) | 11 (44%) | 1 (4%) |
| | *BC/BS plans-M* | 8 (44%) | 0 ( 0%) | 10 (56%) | 0 (0%) |
| **Medically underwritten group policies** | | | | | |
| Hemophilia | *Commercials* | 8 (22%) | 2 ( 5%) | 26 (70%) | 1 (3%) |
| | *HMOs* | 6 (30%) | 1 ( 5%) | 12 (60%) | 1 (5%) |
| | *BC/BS plans-U* | 11 (52%) | 0 ( 0%) | 9 (43%) | 1 (5%) |
| | *BC/BS plans-M* | 7 (47%) | 0 ( 0%) | 8 (53%) | 0 (0%) |
| Tay-Sachs | *Commercials* | 8 (22%) | 2 ( 5%) | 26 (70%) | 1 (3%) |
| | *HMOs* | 5 (25%) | 1 ( 5%) | 13 (65%) | 1 (5%) |
| | *BC/BS plans-U* | 9 (43%) | 0 ( 0%) | 11 (52%) | 1 (5%) |
| | *BC/BS plans-M* | 7 (47%) | 0 ( 0%) | 8 (53%) | 0 (0%) |
| Huntington disease | *Commercials* | 8 (22%) | 2 ( 5%) | 26 (70%) | 1 (3%) |
| | *HMOs* | 5 (25%) | 1 ( 5%) | 13 (65%) | 1 (5%) |
| | *BC/BS plans-U* | 9 (43%) | 0 ( 0%) | 11 (52%) | 1 (5%) |
| | *BC/BS plans-M* | 7 (47%) | 0 ( 0%) | 8 (53%) | 0 (0%) |
| Sickle cell anemia | *Commercials* | 8 (22%) | 2 ( 5%) | 26 (70%) | 1 (3%) |
| | *HMOs* | 7 (35%) | 1 ( 5%) | 11 (55%) | 1 (5%) |
| | *BC/BS plans-U* | 11 (52%) | 0 ( 0%) | 10 (48%) | 0 (0%) |
| | *BC/BS plans-M* | 7 (47%) | 0 ( 0%) | 8 (53%) | 0 (0%) |
| Cystic fibrosis | *Commercials* | 8 (22%) | 2 ( 5%) | 26 (70%) | 1 (3%) |
| | *HMOs* | 6 (30%) | 1 ( 5%) | 12 (60%) | 1 (5%) |
| | *BC/BS plans-U* | 11 (52%) | 0 ( 0%) | 10 (48%) | 0 (0%) |
| | *BC/BS plans-M* | 7 (47%) | 0 ( 0%) | 8 (53%) | 0 (0%) |

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

**Table 3-5—Effect of Genetic Test Results on Insurability: Commercials and HMOs**

How would individual policies and medically underwritten policies normally be affected by the following findings:

| | Respondent | Accepted with standard rates | Accepted with exclusion waiver at standard rates | Accepted with exclusion waiver at rated premium | Accepted without exclusion waiver at rated premium | Declined | No response[a] |
|---|---|---|---|---|---|---|---|
| **Individual policies** | | | | | | | |
| Presymptomatic testing reveals the likelihood of a serious chronic future disease | *Commercials* | 8 (28%) | 1 (4%) | 0 ( 0%) | 0 (0%) | 17 (59%) | 2 ( 8%) |
| | *HMOs* | 2 (18%) | 0 (0%) | 0 ( 0%) | 0 (0%) | 4 (36%) | 5 (46%) |
| Risk oriented testing reveals that an individual carries markers associated with a serious, chronic future disease | *Commercials* | 12 (41%) | 2 (7%) | 2 (7%) | 5 (17%) | 5 (17%) | 3 (10%) |
| | *HMOs* | 4 (36%) | 0 (0%) | 1 (9%) | 0 ( 0%) | 1 ( 9%) | 5 (46%) |
| Carrier testing reveals the possibility that offspring may have a serious, chronic condition or disease | *Commercials* | 16 (55%) | 3 (10%) | 1 ( 4%) | 0 (0%) | 6 (21%) | 3 (10%) |
| | *HMOs* | 6 (55%) | 0 ( 0%) | 1 ( 9%) | 0 (0%) | 0 ( 0%) | 4 (36%) |
| Prenatal diagnosis reveals fetus affected with a serious, chronic condition or disease | *Commercials* | 6 (21%) | 2 (7%) | 0 (0%) | 0 (0%) | 19 (65%) | 2 ( 7%) |
| | *HMOs* | 1 ( 9%) | 0 (0%) | 0 (0%) | 0 (0%) | 4 (36%) | 6 (55%) |
| **Medically underwritten group policies** | | | | | | | |
| Presymptomatic testing reveals the likelihood of a serious chronic future disease | *Commercials* | 10 (27%) | 3 (8%) | 0 (0%) | 1 (3%) | 15 (40%) | 8 (22%) |
| | *HMOs* | 6 (30%) | 0 (0%) | 1 (5%) | 1 (5%) | 5 (25%) | 7 (35%) |
| Risk oriented testing reveals that an individual carries markers associated with a serious, chronic future disease | *Commercials* | 21 (57%) | 3 (8%) | 0 (0%) | 2 (5%) | 4 (11%) | 7 (19%) |
| | *HMOs* | 10 (50%) | 0 (0%) | 1 (5%) | 0 (0%) | 3 (15%) | 6 (30%) |
| Carrier testing reveals the possibility that offspring may have a serious, chronic condition or disease | *Commercials* | 22 (59%) | 3 (8%) | 0 (0%) | 0 (0%) | 4 (11%) | 8 (22%) |
| | *HMOs* | 9 (45%) | 0 (0%) | 2 (10%) | 1 (5%) | 3 (15%) | 5 (25%) |
| Prenatal diagnosis reveals fetus affected with a serious, chronic condition or disease | *Commercials* | 6 (16%) | 1 (3%) | 0 (0%) | 1 (3%) | 24 (65%) | 5 (13%) |
| | *HMOs* | 4 (20%) | 0 (0%) | 0 (0%) | 0 (0%) | 8 (40%) | 8 (40%) |

[a]Percentages may not add to 100 due to rounding.

SOURCE: Office of Technology Assessment, 1992.

effect of such a test result would cause a medically underwritten group application to be declined by 9 of 21 underwriters at BC/BS plans (table 3-6).

Medical directors at 8 of 18 BC/BS plans said they would decline individual coverage if presymptomatic testing revealed predispostion for future, chronic disease predisposition, while 5 would accept the applicant at standard rates. Six of 15 BC/BS plans would decline medically underwritten group coverage because of presymptomatic test results, and 3 would accept the applicant at standard rates.

## Table 3-6—Effect of Genetic Test Results on Insurability: BC/BS plans

How would individual policies and medically underwritten policies normally be affected by the following findings:

| | Respondent | Accepted with standard rates | Accepted with exclusion waiver at standard rates | Accepted with waiting period at standard rates | Accepted with exclusion waiver at rated premium | Accepted without exclusion waiver or waiting period/ rated premium | Accepted with waiting period at rated premium | Declined | No response[a] |
|---|---|---|---|---|---|---|---|---|---|
| **Individual policies** | | | | | | | | | |
| Presymptomatic testing reveals the likelihood of a serious chronic future disease | *BC/BS plans-U*[b] | 6 (24%) | 2 ( 8%) | 3 (12%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 11 (44%) | 3 (12%) |
| | *BC/BS plans-M* | 6 (33%) | 2 (11%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 8 (44%) | 2 (11%) |
| Risk oriented testing reveals that an individual carries markers associated with a serious, chronic future disease | *BC/BS plans-U* | 10 (40%) | 2 ( 8%) | 5 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 5 (20%) | 3 (12%) |
| | *BC/BS plans-M* | 8 (44%) | 1 ( 6%) | 2 (11%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 5 (28%) | 2 (11%) |
| Carrier testing reveals the possibility that offspring may have a serious, chronic condition or disease | *BC/BS plans-U* | 10 (40%) | 2 ( 8%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 3 (12%) | 4 (16%) |
| | *BC/BS plans-M* | 7 (39%) | 2 (11%) | 2 (11%) | 0 ( 0%) | 1 ( 6%) | 0 ( 0%) | 3 (17%) | 3 (17%) |
| Prenatal diagnosis reveals fetus affected with a serious, chronic condition or disease | *BC/BS plans-U* | 5 (20%) | 1 ( 4%) | 1 ( 4%) | 0 (0%) | 0 ( 0%) | 0 ( 0%) | 14 (56%) | 4 (16%) |
| | *BC/BS plans-M* | 3 (17%) | 1 ( 6%) | 0 ( 0%) | 0 (0%) | 0 ( 0%) | 1 ( 6%) | 10 (56%) | 3 (17%) |
| **Medically underwritten group policies** | | | | | | | | | |
| Presymptomatic testing reveals the likelihood of a serious chronic future disease | *BC/BS plans-U* | 6 (29%) | 0 ( 0%) | 3 (14%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 9 (43%) | 3 (14%) |
| | *BC/BS plans-M* | 4 (27%) | 1 ( 7%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 7%) | 6 (40%) | 3 (20%) |
| Risk oriented testing reveals that an individual carries markers associated with a serious, chronic future disease | *BC/BS plans-U* | 9 (43%) | 1 ( 5%) | 5 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 4 (19%) | 2 ( 9%) |
| | *BC/BS plans-M* | 5 (33%) | 1 ( 7%) | 0 ( 0%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 3 (20%) | 3 (20%) |
| Carrier testing reveals the possibility that offspring may have a serious, chronic condition or disease | *BC/BS plans-U* | 9 (43%) | 2 (10%) | 4 (19%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 3 (14%) | 3 (14%) |
| | *BC/BS plans-M* | 4 (27%) | 1 ( 7%) | 1 ( 7%) | 0 ( 0%) | 2 (13%) | 0 ( 0%) | 2 (13%) | 5 (33%) |
| Prenatal diagnosis reveals fetus affected with a serious, chronic condition or disease | *BC/BS plans-U* | 3 (14%) | 0 ( 0%) | 1 ( 5%) | 0 ( 0%) | 1 ( 5%) | 1 ( 5%) | 13 (62%) | 2 ( 9%) |
| | *BC/BS plans-M* | 1 ( 7%) | 0 ( 0%) | 1 ( 7%) | 0 (0%) | 0 ( 0%) | 1 ( 7%) | 9 (60%) | 3 (20%) |

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

Of the 11 HMOs that cover individuals, 4 would decline an applicant if presymptomatic testing revealed the likelihood of a chronic, future disease and 2 would accept the applicant at standard rates. Six of 20 HMOs that cover medically underwritten groups would do so at standard rates, while 5 HMOs would decline the application.

When risk-oriented testing reveals that an individual carries markers associated with a serious, chronic future disease (e.g., predisposition to heart disease) 12 of 29 commercial insurers would accept individual applicants at standard rates; 5 would decline coverage. The use of an exclusion waiver to exclude the condition would be used by four plans, while five plans would use a rated premium rather than an exclusion waiver. More than half of commercial insurers (21 of 37) that cover medically underwritten groups would accept the applicant at standard rates, 8 would offer standard rates but would have an exclusion waiver for the specific condition.

If an individual applicant is found to carry markers for a chronic, future disease, 10 of 25 BC/BS plans represented by an underwriter survey would accept the application at standard rates, while 5 would decline coverage. Similar proportions were found for medically underwritten group coverage, with underwriters at 9 of 21 BC/BS plans responding that an application would be accepted at standard rates, and 4 responding that coverage would be declined.

The results of risk-oriented testing did not affect individual insurability at 8 of 18 BC/BS plans represented by the medical director population, as they would be accepted with standard rates. However, medical directors at 5 of 18 plas said they would decline coverage because of evidence of disease markers. One-third of underwriters at BC/BS plans (5 of 15) that cover medically underwritten groups said they would accept such groups at standard rates even if disease markers were detected within the group; 3 would decline such applications.

Four of 11 HMOs that accept individuals for coverage would still do so at standard rates even if risk-oriented testing revealed the possibility of a serious, chronic future disease. Half of the HMOs (10 of 20) that cover medically underwritten groups would do so at standard rates in light of such risk-oriented testing results; 3 would deny the application.

When carrier tests reveal the possibility that children may have a serious, chronic condition or disease, 16 of 29 commercial insurers would accept the applicant with standard rates, but 6 would decline the applicant. Three commercial insurers would accept the individual applicant with an exclusion waiver (presumably for the specific condition revealed by carrier testing). Over half of commercial insurers that provide coverage to medically underwritten groups (22 of 37) would accept the applicant with standard rates, while 8 would decline coverage.

Ten of 25 BC/BS plans represented by the underwriter population would accept an individual applicant at standard rates even if carrier tests revealed that children might have a serious condition or disease; 3 would decline coverage. A waiting period would be used by six BC/BS plans for individual applicants. Nine of 21 BC/BS plans represented by a medical director survey would provide coverage at standard rates to medically underwritten groups with members who had carrier test results; 4 would require a waiting period.

Results of carrier testing would not affect insurability or rating for individual applicants at 7 of 18 BC/BS plans represented by a medical director survey, while 2 plans would require an exclusion waiver and 2 would require a waiting period. Similar proportions were found for medical directors at BC/BS plans (table 3-6).

Carrier test results would not cause any of the 11 HMOs that accept individual applicants to decline coverage; 6 would accept at standard rates and one HMO would accept the applicant with an exclusion waiver and charge a rated premium. Nine of the 20 HMOs that provide medically underwritten group coverage would do so at standard rates in light of carrier test results, and three would decline coverage.

If prenatal diagnosis reveals a fetus is affected with a serious, chronic condition or disease, 19 of 29 commercial insurers would decline an applicant. Six commercial insurers would accept the individual applicant at standard rates. It should be noted however, that if a pregnant woman is already covered, her baby is covered at birth (1), so the prenatal diagnosis would affect coverage only for pregnant women who are not currently covered. Twenty-four of 37 commercial insurers that cover

**Table 3-7—Effect of Genetic Test Information on Insurability: Commercials and HMOs**

For *individual policy applicants only*, how would the application normally be treated if a policy applicant was asymptomatic but had a family history of:

| | Respondent | Accepted with standard rates | Accepted with exclusion waiver at standard rates | Accepted with exclusion waiver at rated premium | Accepted without exclusion waiver but at rated premium | Declined | No response[a] |
|---|---|---|---|---|---|---|---|
| Hemophilia | *Commercials* | 26 (90%) | 1 ( 3%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 7%) |
| | *HMOs* | 10 (91%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 9%) |
| Tay-Sachs | *Commercials* | 25 (86%) | 1 ( 3%) | 0 ( 0%) | 0 ( 0%) | 1 ( 3%) | 2 ( 7%) |
| | *HMOs* | 10 (91%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 9%) |
| Huntington disease | *Commercials* | 17 (59%) | 3 (10%) | 0 ( 0%) | 0 ( 0%) | 6 (21%) | 3 (10%) |
| | *HMOs* | 9 (82%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 9%) | 1 ( 9%) |
| Sickle cell anemia | *Commercials* | 23 (79%) | 1 ( 3%) | 0 ( 0%) | 1 ( 3%) | 2 ( 7%) | 2 ( 7%) |
| | *HMOs* | 10 (91%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 9%) |
| Cystic fibrosis | *Commercials* | 26 (90%) | 1 ( 3%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 7%) |
| | *HMOs* | 10 (91%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 (91%) |
| Duchenne muscular dystrophy | *Commercials* | 23 (79%) | 2 ( 7%) | 0 ( 0%) | 0 ( 0%) | 1 ( 3%) | 3 (10%) |
| | *HMOs* | 10 (91%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 9%) |
| ADA deficiency | *Commercials* | 25 (86%) | 1 ( 3%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 3 (10%) |
| | *HMOs* | 10 (91%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 9%) |
| Down syndrome | *Commercials* | 27 (93%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 7%) |
| | *HMOs* | 10 (91%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 9%) |

[a]Percentages may not add to 100 due to rounding.

SOURCE: Office of Technology Assessment, 1992.

medically underwritten groups would decline coverage, while 6 would accept at standard rates.

Underwriters at 14 of 25 BC/BS plans would decline coverage to individual applicants if prenatal diagnosis revealed the fetus had a serious condition or disease, 5 would accept the applicant at standard rates. Thirteen of 21 BC/BS plans represented by the underwriter population would decline a medically underwritten group application as a result of such a prenatal diagnosis. A similar distribution of medical directors would decline coverage due to prenatal test results (table 3-6).

Four of 11 HMOs that offer individual coverage would decline an applicant if prenatal test results revealed a fetus had a serious condition, and only 1 would accept the applicant at standard rates. Eight of 20 HMOs that cover medically underwritten groups would decline the application, while 4 HMOs would accept the application with standard rates.

### *Effect of Genetic Information on Insurability*

How do health insurers treat applicants that are asymptomatic but have family histories of genetic conditions? OTA found that a family history of a genetic condition did not always mean the applicant would be declined. In fact, the majority of such applicants would be accepted at standard rates. The majority of commercial insurers accepted individual applicants at standard rates when a family history of a genetic condition was revealed (table 3-7). Applicants for commercial health insurance who had a family history of hemophilia, Tay-Sachs, sickle cell anemia, CF, ADA deficiency (''Bubble Boy disease''), and Down syndrome all would be accepted at standard rates more than 80 percent of the time. Fifty-nine percent of individual applicants for commercial insurance with a family history of Huntington disease and 79 percent with a history of Duchenne muscular dystrophy would be accepted at standard rates. The majority of HMOs accepted individual applicants at standard rates when they were asymptomatic, but had a family history of a genetic condition (table 3-7). The majority of underwriters and medical directors from BC/BS plans responding to the OTA survey accepted individual applicants at standard rates regardless of family history for genetic conditions (table 3-8).

## Table 3-8—Effect of Genetic Information on Insurability: BC/BS plans

For *individual policy applicants only*, how would the application normally be treated If a policy applicant was asymptomatic but had a family history of:

| | Respondent | Accepted with standard rates | Accepted with exclusion waiver at standard rates | Accepted with waiting period at standard rates | Accepted with exclusion waiver at rated premium | Accepted without exclusion waiver or waiting period/ rated premium | Accepted with waiting period at rated premium | Declined | No response[a] |
|---|---|---|---|---|---|---|---|---|---|
| Hemophilia | *BC/BS plans-U*[b] | 16 (64%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 8%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| Tay-Sachs | *BC/BS plans-U* | 16 (64%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 8%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| Huntington disease | *BC/BS plans-U* | 15 (60%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 3 (12%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| Sickle cell anemia | *BC/BS plans-U* | 16 (64%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 8%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| Cystic fibrosis | *BC/BS plans-U* | 16 (64%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 8%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| Duchenne muscular dystrophy | *BC/BS plans-U* | 16 (64%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 8%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| ADA deficiency | *BC/BS plans-U* | 16 (64%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 8%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| Down syndrome | *BC/BS plans-U* | 17 (68%) | 1 ( 4%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (30%) | 0 ( 0%) | 0 ( 0%) | 1 ( 7%) | 1 ( 7%) | 1 ( 7%) |

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

**Table 3-9—Coverage of a Family Member with Family History of Disease: Commercials and HMOs**

For *individual policy applicants only*, how would the coverage of a family member (e.g., spouse or adopted child) be affected if the policy applicant was negative, but the family member was asymptomatic but had a family history of:

| | Respondent | Accepted with standard rates | Accepted with exclusion waiver at standard rates | Accepted with exclusion waiver at rated premium | Accepted without exclusion waiver but at rated premium | Declined | No response[a] |
|---|---|---|---|---|---|---|---|
| Hemophilia | *Commercials* | 26 (90%) | 1 ( 3%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 7%) |
| | *HMOs* | 8 (73%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 3 (27%) |
| Tay-Sachs | *Commercials* | 25 (86%) | 2 ( 7%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 7%) |
| | *HMOs* | 8 (73%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 3 (27%) |
| Huntington disease | *Commercials* | 18 (62%) | 3 (10%) | 0 ( 0%) | 0 ( 0%) | 5 (17%) | 3 (10%) |
| | *HMOs* | 7 (64%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 9%) | 3 (27%) |
| Sickle cell anemia | *Commercials* | 25 (86%) | 1 ( 3%) | 0 ( 0%) | 1 ( 3%) | 0 ( 0%) | 2 ( 7%) |
| | *HMOs* | 8 (73%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 3 (27%) |
| Cystic fibrosis | *Commercials* | 26 (90%) | 1 ( 3%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 7%) |
| | *HMOs* | 8 (73%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 3 (27%) |
| Duchenne muscular dystrophy | *Commercials* | 25 (86%) | 1 ( 3%) | 0 ( 0%) | 0 ( 0%) | 1 ( 3%) | 2 ( 7%) |
| | *HMOs* | 8 (73%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 3 (27%) |
| ADA deficiency | *Commercials* | 26 (90%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 3%) | 2 ( 7%) |
| | *HMOs* | 8 (73%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 3 (27%) |
| Down syndrome | *Commercials* | 26 (90%) | 0 ( 0%) | 1 ( 3%) | 0 ( 0%) | 0 ( 0%) | 2 ( 7%) |
| | *HMOs* | 8 (73%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 3 (27%) |

[a]Percentages may not add to 100 due to rounding.

SOURCE: Office of Technology Assessment, 1992.

How would coverage decisions be handled for a family member on an individual insurance policy when the applicant had a family member who was asymptomatic but had a family history of genetic conditions? Commercial insurers appear to handle applications the same whether it is a family member or the individual applying for the policy who has the family history of genetic disease (table 3-9): The majority of applications would be accepted at standard rates regardless of the specific genetic condition. Similar results were found for responding HMOs, as well as underwriters and medical directors from BC/BS plans (table 3-10).

## CHAPTER 3 REFERENCES

1. Payne, J., Health Insurance Association of America, Inc., Washington, DC, personal communication, January 1992.
2. U.S. Congress, Office of Technology Assessment, *Medical Testing and Health Insurance*, OTA-H-384 (Washington, DC: U.S. Government Printing Office, August 1988).
3. U.S. Congress, Office of Technology Assessment, *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening*, OTA-BA-532 (Washington, DC: U.S. Government Printing Office, August 1992).

## Table 3-10—Coverage of a Family Member with a Family History of Disease: BC/BS plans

For *individual policy applicants only*, how would the coverage of a family member (e.g., spouse or adopted child) be affected if the policy applicant was negative, but the family member was asymptomatic but had a family history of:

| | Respondent | Accepted with standard rates | Accepted with exclusion waiver at standard rates | Accepted with waiting period at standard rates | Accepted with exclusion waiver at rated premium | Accepted without exclusion waiver or waiting period/ rated premium | Accepted with waiting period at rated premium | Declined | No response[a] |
|---|---|---|---|---|---|---|---|---|---|
| Hemophilia | *BC/BS plans-U*[b] | 16 (64%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 8%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| Tay-Sachs | *BC/BS plans-U* | 16 (64%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 8%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| Huntington disease | *BC/BS plans-U* | 15 (60%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 3 (12%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| Sickle cell anemia | *BC/BS plans-U* | 16 (64%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 8%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| Cystic fibrosis | *BS/BC plans-U* | 16 (64%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 8%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| Duchenne muscular dystrophy | *BC/BS plans-U* | 16 (64%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 8%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| ADA deficiency | *BC/BS plans-U* | 16 (64%) | 0 ( 0%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 ( 8%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (20%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 2 (13%) | 1 ( 7%) |
| Down syndrome | *BC/BS plans-U* | 17 (68%) | 1 ( 4%) | 6 (24%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 0 ( 0%) | 1 ( 4%) |
| | *BC/BS plans-M* | 9 (60%) | 0 ( 0%) | 3 (30%) | 0 ( 0%) | 0 ( 0%) | 1 ( 7%) | 1 ( 7%) | 1 ( 7%) |

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

Will health insurers pay for voluntary screening and followup counseling? And will health insurance companies authorize payment for prenatal screening or testing of newborn children? Answers to these questions carry significant cost implications. They also will likely affect the degree to which carrier screening for cystic fibrosis (CF) becomes commonplace, since many people will be unwilling to pay out-of-pocket the costs of the assays (1). From the perspective of the commercial laboratory that provides genetic tests to medical providers and patients, the issue of reimbursement is crucial to business—current and future.

OTA asked health insurers covering individuals and medically underwritten groups about their coverage of certain genetic tests and services. Are they covered "at patient request," where there is no family history (i.e., screening)? Are they covered "only if medically indicated," where a family history exists? Or, are they "not covered"?

## REIMBURSEMENT FOR GENETIC TESTS AND SERVICES

No commercial company reimburses for CF carrier tests for screening purposes. The survey also found that carrier tests for CF—as well as for Tay-Sachs and sickle cell—are not covered for any reason by 12 of 29 commercial insurers that offer individual coverage. Twelve respondents (41 percent) cover CF carrier assays if medically indicated. With respect to prenatal tests for CF, about 41 percent (12 respondents) that write individual policies reimburse for such tests when medically indicated.

For the 37 commercial companies offering medically underwritten group policies, carrier tests for CF (and, again, for sickle cell or Tay-Sachs) are not covered by any company when done solely at patient request. CF mutation analysis is covered by 24 of 37 companies if medically indicated. Ten companies offering medically underwritten group coverage do not cover any of the carrier or prenatal tests asked about in OTA's survey. Sixty-two percent of companies (23 respondents) that offer medically underwritten group policies cover prenatal tests for CF when medically indicated (table 4-1).

Two of 25 Blue Cross and Blue Shield (BC/BS) plans offering individual coverage would reimburse CF carrier screening at patient request. Sixteen of these BC/BS plans (64 percent) cover them if they are medically indicated and seven do not cover them. Three of 25 BC/BS plans cover prenatal testing for CF at a patient's request, seven if medically indicated, and three not at all. Of 21 BC/BS plans offering coverage to medically underwritten groups, CF carrier screening is covered at patient request by only 2 companies (10 percent), if medically indicated by 11 companies (52 percent), and not at all by 8 companies (38 percent) (table 4-1). Data on coverage for CF prenatal tests by BC/BS plans that cover medically underwritten groups are also presented in table 4-1.

For the 11 health maintenance organizations (HMOs) that offer health insurance to individuals, 1 HMO (9 percent) covers CF carrier tests at patient request and 7 HMOs (64 percent) reimburse for them if medically indicated. For the 20 HMOs that offer medically underwritten group contracts, 1 HMO (5 percent) covers CF carrier tests at patient request, 13 respondents (45 percent) reimburse for them if medically indicated, and 2 (10 percent) do not cover them at all. Table 4-1 presents these results as well as how HMOs cover prenatal tests for CF.

From OTA's survey results, it is evident that carrier and prenatal tests often are not covered under individual and medically underwritten group policies unless they are medically necessary—i.e., unless a family history exists. Such policies can have a significant impact on both the rate at which CF carrier screening becomes routine and the ultimate utilization of CF mutation analysis.

OTA found that genetic counseling was not covered by 18 commercial companies offering individual coverage and 17 offering medically underwritten group coverage. Six commercial insurance companies offering individual policies and 16 that medically underwrite groups cover genetic counseling only if it is medically indicated. Two commercial companies offering each type of cover-

**Table 4-1—Reimbursement for Genetic Tests and Genetic Counseling**

| Question | Respondent | At patient request | Medically indicated only | Not covered | No response[a] |
|---|---|---|---|---|---|
| **Do your standard individual policies and medically underwritten policies provide coverage for:** | | | | | |
| **Individual policies** | | | | | |
| Carrier tests for CF? | *Commercials* | 0 ( 0%) | 12 (41%) | 12 (41%) | 5 (18%) |
| | *HMOs* | 2 (18%) | 7 (64%) | 0 ( 0%) | 2 (18%) |
| | *BC/BS plans-U*[b] | 2 ( 8%) | 16 (64%) | 7 (28%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 11 (61%) | 5 (28%) | 2 (11%) |
| Carrier tests for Tay-Sachs? | *Commercials* | 0 ( 0%) | 12 (41%) | 12 (41%) | 5 (18%) |
| | *HMOs* | 2 (18%) | 7 (64%) | 0 ( 0%) | 2 (18%) |
| | *BC/BS plans-U* | 2 ( 8%) | 16 (64%) | 7 (28%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 11 (61%) | 5 (28%) | 2 (11%) |
| Carrier tests for sickle cell trait? | *Commercials* | 0 ( 0%) | 12 (41%) | 12 (41%) | 5 (18%) |
| | *HMOs* | 3 (27%) | 6 (55%) | 0 ( 0%) | 2 (18%) |
| | *BC/BS plans-U* | 2 ( 8%) | 16 (64%) | 7 (28%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 11 (61%) | 5 (28%) | 2 (11%) |
| Prenatal tests for CF? | *Commercials* | 0 ( 0%) | 12 (41%) | 14 (48%) | 3 (10%) |
| | *HMOs* | 1 ( 9%) | 7 (64%) | 1 ( 9%) | 2 (18%) |
| | *BC/BS plans-U* | 3 (12%) | 19 (76%) | 3 (12%) | 0 ( 0%) |
| | *BC/BS plans-M* | 1 ( 5%) | 13 (73%) | 2 (11%) | 2 (11%) |
| Prenatal tests for Tay-Sachs? | *Commercials* | 0 ( 0%) | 11 (38%) | 15 (52%) | 3 (10%) |
| | *HMOs* | 2 (18%) | 8 (73%) | 0 ( 0%) | 1 ( 9%) |
| | *BC/BS plans-U* | 3 (12%) | 19 (76%) | 3 (12%) | 0 ( 0%) |
| | *BC/BS plans-M* | 1 ( 5%) | 13 (73%) | 2 (11%) | 2 (11%) |
| Prenatal tests for sickle cell anemia? | *Commercials* | 0 ( 0%) | 11 (38%) | 15 (52%) | 3 (10%) |
| | *HMOs* | 1 ( 9%) | 8 (73%) | 0 ( 0%) | 2 (18%) |
| | *BC/BS plans-U* | 3 (12%) | 19 (76%) | 3 (12%) | 0 ( 0%) |
| | *BC/BS plans-M* | 1 ( 5%) | 13 (73%) | 2 (11%) | 2 (11%) |
| Prenatal tests for Down syndrome? | *Commercials* | 1 ( 4%) | 10 (34%) | 15 (52%) | 3 (10%) |
| | *HMOs* | 1 ( 9%) | 9 (82%) | 0 ( 0%) | 1 ( 9%) |
| | *BC/BS plans-U* | 3 (12%) | 19 (76%) | 3 (12%) | 0 ( 0%) |
| | *BC/BS plans-M* | 1 ( 5%) | 13 (73%) | 2 (11%) | 2 (11%) |
| Genetic counseling? | *Commercials* | 2 ( 7%) | 6 (21%) | 18 (62%) | 3 (10%) |
| | *HMOs* | 1 ( 9%) | 6 (56%) | 1 ( 9%) | 3 ( 9%) |
| | *BC/BS plans-U* | 1 ( 4%) | 9 (36%) | 13 (52%) | 2 ( 8%) |
| | *BC/BS plans-M* | 0 ( 0%) | 8 (44%) | 8 (44%) | 2 (12%) |

age (individual and medically underwritten) reimburse for genetic counseling performed at patient request (table 4-1). Similar results for BC/BS plans and HMOs are also presented in table 4-1.

## COVERAGE FOR CYSTIC FIBROSIS CARRIER TESTS

In contrast to questions that inquire about what the respondent's company policy would be, respondents were also asked whether they were aware if their organization had ever actually reimbursed for CF carrier tests. Regardless of the type of respondent, CF carrier testing has been reimbursed at roughly the same frequency for all (table 4-2). For commercial insurers, 11 of the 51 respondents (22 percent) said their companies had reimbursed for such tests, and 35 respondents (69 percent) indicated their companies had not. Of the 23 HMOs that responded to the OTA survey, 7 (30 percent) had reimbursed for CF carrier testing, and 14 (61 percent) had not. Of the 29 BC/BS plans represented by the underwriter survey, 7 (24 percent) had reimbursed for CF carrier testing, and 18 (62 percent) had not. Five of the 18 (28 percent) BC/BS plans represented by a medical director survey had reimbursed for CF carrier testing, and 12 (67 percent) had not.

**Table 4-1—Reimbursement for Genetic Tests and Genetic Counseling—Continued**

| Question | Respondent | At patient request | Medically indicated only | Not covered | No response[a] |
|---|---|---|---|---|---|
| **Medically underwritten groups** | | | | | |
| Carrier tests for CF? | *Commercials* | 0 ( 0%) | 24 (65%) | 10 (27%) | 3 ( 8%) |
| | *HMOs* | 1 ( 5%) | 13 (65%) | 2 (10%) | 4 (20%) |
| | *BC/BS plans-U* | 2 (10%) | 11 (52%) | 8 (38%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 9 (60%) | 4 (27%) | 2 (13%) |
| Carrier tests for Tay-Sachs? | *Commercials* | 0 ( 0%) | 22 (59%) | 11 (30%) | 4 (11%) |
| | *HMOs* | 1 (10%) | 13 (60%) | 2 (10%) | 7 (20%) |
| | *BC/BS plans-U* | 2 (10%) | 11 (52%) | 8 (38%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 9 (60%) | 4 (27%) | 2 (13%) |
| Carrier tests for sickle cell trait? | *Commercials* | 0 ( 0%) | 23 (62%) | 10 (27%) | 4 (11%) |
| | *HMOs* | 2 (10%) | 12 (60%) | 2 (10%) | 4 (20%) |
| | *BC/BS plans-U* | 2 (10%) | 11 (52%) | 8 (38%) | 0 ( 0%) |
| | *BC/BS plans-M* | 0 ( 0%) | 9 (60%) | 4 (27%) | 2 (13%) |
| Prenatal tests for CF? | *Commercials* | 1 ( 3%) | 23 (62%) | 10 (27%) | 3 ( 8%) |
| | *HMOs* | 2 (10%) | 14 (70%) | 0 ( 0%) | 4 (20%) |
| | *BC/BS plans-U* | 3 (14%) | 14 (67%) | 4 (19%) | 0 ( 0%) |
| | *BC/BS plans-M* | 1 ( 7%) | 11 (73%) | 1 ( 7%) | 2 (13%) |
| Prenatal tests for Tay-Sachs? | *Commercials* | 1 ( 3%) | 24 (65%) | 10 (27%) | 2 ( 5%) |
| | *HMOs* | 3 (15%) | 14 (70%) | 0 ( 0%) | 3 (15%) |
| | *BC/BS plans-U* | 3 (14%) | 14 (67%) | 4 (19%) | 0 ( 0%) |
| | *BC/BS plans-M* | 1 ( 7%) | 11 (73%) | 1 ( 7%) | 2 (13%) |
| Prenatal tests for sickle cell anemia? | *Commercials* | 1 ( 3%) | 24 (65%) | 10 (27%) | 2 ( 5%) |
| | *HMOs* | 2 (10%) | 14 (70%) | 0 ( 0%) | 4 (20%) |
| | *BC/BS plans-U* | 3 (14%) | 14 (67%) | 4 (19%) | 0 ( 0%) |
| | *BC/BS plans-M* | 1 ( 7%) | 11 (73%) | 1 ( 7%) | 2 (13%) |
| Prenatal tests for Down syndrome? | *Commercials* | 2 ( 5%) | 23 (62%) | 10 (27%) | 2 ( 5%) |
| | *HMOs* | 2 (10%) | 15 (75%) | 0 ( 0%) | 3 (15%) |
| | *BC/BS plans-U* | 3 (14%) | 14 (67%) | 4 (19%) | 0 ( 0%) |
| | *BC/BS plans-M* | 1 ( 7%) | 11 (73%) | 1 ( 7%) | 2 (13%) |
| Genetic counseling | *Commercials* | 2 ( 5%) | 16 (43%) | 17 (46%) | 2 ( 5%) |
| | *HMOs* | 2 (10%) | 12 (60%) | 1 ( 5%) | 5 (25%) |
| | *BC/BS plans-U* | 1 ( 5%) | 7 (33%) | 12 (57%) | 1 ( 5%) |
| | *BC/BS plans-M* | 0 ( 0%) | 6 (40%) | 7 (47%) | 2 (13%) |

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

## ECONOMIC ANALYSIS OF GENETIC TESTS

To determine whether insurance companies have looked into the economic implications of various genetic tests, OTA asked if companies had ever conducted an economic analysis of the costs and benefits of various testing schemes. OTA found that no commercial insurer had conducted an economic analysis of the costs and benefits of carrier or other genetic tests as part of applicant screening. In addition, no commercial company had conducted an economic analysis of the costs and benefits of genetic counseling of carriers who are covered. One commercial company reported it had done an analysis of the costs and benefits of carrier tests as part of prenatal coverage, but 48 of 51 companies had not (table 4-3).

Survey respondents from HMOs had not conducted an economic analysis of the costs and benefits of carrier testing for either applicant screening or prenatal coverage. No economic analysis had been conducted by HMOs on genetic testing for applicant screening. One company conducted an economic analysis of the costs and benefits of genetic counseling of carriers who are covered.

Similar results were found for BC/BS plans. One of the 29 BC/BS plans represented by an underwriter

**Table 4-2—Coverage for Cystic Fibrosis Carrier Tests**

| Respondent | Yes | No | No response[a] |
|---|---|---|---|
| Commercials | 11 (22%) | 35 (69%) | 5 ( 9%) |
| HMOs | 7 (30%) | 14 (61%) | 2 ( 9%) |
| BC/BS plans-U[b] | 7 (24%) | 18 (62%) | 4 (14%) |
| BC/BS plans-M | 5 (28%) | 12 (67%) | 1 ( 5%) |

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

survey had conducted an economic analysis of the costs and benefits of genetic counseling of carriers who are covered, and 1 had conducted an economic analysis of carrier testing as part of prenatal coverage. None of the BC/BS plans represented by the underwriter survey had conducted an economic analysis of carrier or genetic testing as a part of applicant screening.

One of the 18 BC/BS plans represented by the medical director survey had conducted an economic analysis of carrier testing as part of prenatal coverage. Otherwise, none of the medical directors at the responding BC/BS plans had conducted an economic analysis of carrier or genetic testing as part of applicant screening, or of genetic counseling of carriers who are covered.

## PERSPECTIVES ON FUTURE REIMBURSEMENT FOR GENETIC TESTS

As new genetic tests come on line, will insurers alter their claims payment practices? When asked if they would alter claims payment practices in the next 5 years, nearly half of commercial insurers (23 of 51; 45 percent) considered it "very unlikely," while one quarter (12; 24 percent) found it "somewhat likely"; only two companies thought it was likely (table 4-4). When commercial insurers were asked to project ahead a decade, 23 of 51 companies responded that it would be very or somewhat likely that their company would alter claims payment practices as new genetic tests came on line; 28 companies thought it would be somewhat or very unlikely.

Underwriters from 10 BC/BS plans responded it was "somewhat likely" that claims payment practices would be altered as new genetic tests came on line, 9 thought it "somewhat unlikely" and 7 thought it was "very unlikely." More BC/BS underwriters thought it was "somewhat likely" (11 of 29) in 10 years. Six BC/BS plans represented by an underwriter survey thought it was "very likely" and seven thought it "very unlikely."

**Table 4-3—Economic Analyses of Genetic Tests and Genetic Counseling by Insurers**

| Question | Respondent | Yes | No | No response[a] |
|---|---|---|---|---|
| **Has your company ever conducted an economic analysis of:** | | | | |
| Carrier testing as part of applicant screening? | *Commercials* | 0 ( 0%) | 50 (98%) | 1 ( 2%) |
| | *HMOs* | 0 ( 0%) | 20 (87%) | 3 (13%) |
| | *BC/BS plans-U[b]* | 0 ( 0%) | 28 (94%) | 1 ( 3%) |
| | *BC/BS plans-M* | 0 ( 0%) | 16 (89%) | 2 (11%) |
| Carrier testing as part of prenatal coverage? | *Commercials* | 1 ( 2%) | 48 (94%) | 2 ( 4%) |
| | *HMOs* | 0 (10%) | 20 (87%) | 3 (13%) |
| | *BC/BS plans-U* | 1 (13%) | 27 (94%) | 1 (13%) |
| | *BC/BS plans-M* | 1 ( 6%) | 15 (83%) | 2 (11%) |
| Genetic testing as part of applicant screening? | *Commercials* | 0 ( 0%) | 49 (96%) | 2 ( 4%) |
| | *HMOs* | 0 ( 0%) | 20 (87%) | 3 (13%) |
| | *BC/BS plans-U* | 0 ( 0%) | 28 (97%) | 1 ( 3%) |
| | *BC/BS plans-M* | 0 ( 0%) | 16 (89%) | 2 (11%) |
| Genetic counseling of carriers who are covered? | *Commercials* | 0 ( 0%) | 49 (96%) | 2 ( 4%) |
| | *HMOs* | 1 ( 4%) | 19 (83%) | 3 (13%) |
| | *BC/BS plans-U* | 1 ( 3%) | 27 (94%) | 1 ( 3%) |
| | *BC/BS plans-M* | 0 ( 0%) | 16 (89%) | 2 (11%) |

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

Medical directors from 4 of 18 BC/BS plans responded that it was "somewhat likely" that claims payment practices would be altered as new genetic tests came on line. However, nine medical directors from BC/BS plans thought it was "somewhat unlikely" that payment practices would be altered. In 10 years, seven underwriters from BC/BS plans thought it was "somewhat likely" and six thought it was "somewhat unlikely" (table 4-4).

Seven of 23 HMOs thought it was "very likely" or "somewhat likely" that they would alter their claims payment practices as new genetic tests came on line, nine HMOs thought it would be "very unlikely" and five responded it would be "somewhat unlikely." In 10 years, only two HMOs thought it would be "very likely" they would alter claims payment practices, five HMOs responded it would be "somewhat likely," eight thought it would be "somewhat unlikely" and five thought it would be "very unlikely."

## CHAPTER 4 REFERENCES


1. U.S. Congress, Office of Technology Assessment, *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening*, OTA-BA-532 (Washington, DC: U.S. Government Printing Office, August 1992).
2. U.S. Congress, Office of Technology Assessment, *Genetic Counseling and Cystic Fibrosis Carrier Screening—Results of a Survey*, OTA-BP-BA-97 (Washington, DC: U.S. Government Printing Office, September 1992).


**Table 4-4—Projected Reimbursement Practices by Insurers in 5 and 10 Years**

| Question | Respondent | Very likely | Somewhat likely | Somewhat unlikely | Very unlikely | No response[a] |
|---|---|---|---|---|---|---|
| **How likely do you think it is that your company/HMO will in the next 5 years:** | | | | | | |
| Alter claims payment practices as new genetic tests come on line | *Commercials* | 7 (14%) | 12 (24%) | 16 (31%) | 16 (31%) | 0 ( 0%) |
| | *HMOs* | 1 ( 4%) | 5 (22%) | 9 (39%) | 6 (26%) | 2 ( 9%) |
| | *BC/BS plans-U*[b] | 1 ( 5%) | 10 (34%) | 9 (31%) | 7 (24%) | 2 ( 6%) |
| | *BC/BS plans-M* | 1 ( 6%) | 4 (22%) | 9 (50%) | 2 (11%) | 2 (11%) |
| **In the next 10 years:** | | | | | | |
| Alter claims payment practices as new genetic tests come on line | *Commercials* | 7 (14%) | 12 (24%) | 16 (31%) | 16 (31%) | 0 ( 0%) |
| | *HMOs* | 1 ( 4%) | 5 (22%) | 9 (26%) | 6 (26%) | 2 ( 9%) |
| | *BC/BS plans-U* | 6 (22%) | 11 (38%) | 3 (10%) | 7 (24%) | 2 ( 6%) |
| | *BC/BS plans-M* | 1 ( 6%) | 7 (39%) | 6 (33%) | 2 (11%) | 2 (11%) |

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

# General Attitudes Toward Genetic Tests and Information

Besides current or anticipated reimbursement practices for genetic tests, OTA also asked several questions to gauge health insurers' general attitudes toward genetic tests and genetic information. This chapter reports results from these questions. Additionally, general attitudes of respondents can be gleaned from the verbatim comments offered by some respondents, presented in appendix B.

## IMPACT OF GENETIC TESTS ON BUSINESS PRACTICES

As genetic tests become widely available, one important consideration for insurers will be the financial impact such tests might have on their business. OTA asked survey participants about whether they believed certain scenarios involving the availability of genetic tests would lead to a negative financial impact for their company.

The majority of commercial insurers (30 of 51; 59 percent) said a negative financial impact would not occur if genetic tests were widely available to the medical community. A majority of chief underwriters at Blue Cross and Blue Shield (BC/BS) plans (20 of 29; 69 percent) responded similarly, as did 6 of 18 medical directors at BC/BS plans (33 percent). Respondents from health maintenance organizations (HMOs), however, were equally divided in their opinions of whether widespread availability of genetic tests to the medical provider community would result in a negative financial impact for their HMOs (table 5-1).

In contrast, table 5-1 shows that a clear majority of respondents from commercial insurers, BC/BS plans, and HMOs thought a negative financial impact would likely occur if genetic tests were widely available, but had constraints on insurers' access to the results. Similarly, a majority of survey respondents from all populations clearly thought a negative financial impact would result for their companies if the availability of genetic tests resulted in adverse claims or underwriting results due to adverse selection (table 5-1). A handful of respondents among the total survey population also wrote in that a negative financial impact also would be likely if genetic tests became mandated benefits for which they would not ordinarily have reimbursed.

## ATTITUDES TOWARD GENETIC INFORMATION

As discussed in chapter 3, health insurers that offer individual or medically underwritten group policies clearly weigh several factors in determining both insurability and rating. Included among the factors that respondents considered "very impor-

**Table 5-1—Impact of Genetic Tests on Insurers**

| Question | Respondent | Yes | No | No response[a] |
|---|---|---|---|---|
| **Under what conditions would a negative financial impact be likely to occur for your company (check all that apply):** | | | | |
| Widespread availability of genetic tests to the medical provider community. | *Commercials* | 19 (37%) | 30 (59%) | 2 ( 4%) |
| | *HMOs* | 10 (44%) | 10 (44%) | 3 (13%) |
| | *BC/BS plans-U*[b] | 7 (24%) | 20 (69%) | 2 ( 7%) |
| | *BC/BS plans-M* | 6 (33%) | 11 (61%) | 1 ( 6%) |
| Widespread availability of genetic tests with constraints on insurers' access to results. | *Commercials* | 34 (67%) | 15 (29%) | 2 ( 4%) |
| | *HMOs* | 16 (70%) | 4 (17%) | 3 (13%) |
| | *BC/BS plans-U* | 17 (59%) | 10 (35%) | 2 ( 7%) |
| | *BC/BS plans-M* | 11 (61%) | 6 (33%) | 1 ( 6%) |
| Adverse claims or underwriting results from antiselection. | *Commercials* | 47 (92%) | 2 ( 4%) | 2 ( 4%) |
| | *HMOs* | 18 (78%) | 2 ( 9%) | 3 (13%) |
| | *BC/BS plans-U* | 27 (93%) | 0 ( 0%) | 2 ( 7%) |
| | *BC/BS plans-M* | 16 (89%) | 1 ( 6%) | 1 ( 6%) |

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

**Table 5-2—Genetic Information as Medical Information or Preexisting Conditions**

| Question | Respondent | Agree strongly | Agree somewhat | Disagree somewhat | Disagree strongly | No response[a] |
|---|---|---|---|---|---|---|
| Genetic information is no different than other types of medical information | *Commercials* | 17 (33%) | 10 (20%) | 12 (23%) | 10 (20%) | 2 ( 4%) |
| | *HMOs* | 7 (30%) | 6 (26%) | 5 (22%) | 3 (13%) | 2 ( 9%) |
| | *BC/BS plans-U*[b] | 6 (21%) | 14 (48%) | 6 (21%) | 1 ( 3%) | 2 ( 7%) |
| | *BC/BS plans-M* | 5 (28%) | 5 (28%) | 4 (22%) | 2 (11%) | 2 (11%) |
| Genetic conditions such as cystic fibrosis or Huntington disease are preexisting conditions | *Commercials* | 14 (28%) | 9 (18%) | 17 (33%) | 8 (16%) | 3 ( 6%) |
| | *HMOs* | 12 (52%) | 8 (35%) | 1 ( 4%) | 0 ( 0%) | 2 ( 9%) |
| | *BC/BS plans-U* | 8 (28%) | 7 (24%) | 8 (28%) | 5 (17%) | 1 ( 3%) |
| | *BC/BS plans-M* | 10 (56%) | 2 (11%) | 3 (17%) | 1 ( 6%) | 2 (11%) |
| Carrier status for genetic conditions such as cystic fibrosis or Tay-Sachs are preexisting conditions | *Commercials* | 8 (16%) | 12 (24%) | 16 (31%) | 13 (25%) | 2 ( 4%) |
| | *HMOs* | 5 (22%) | 12 (52%) | 0 ( 0%) | 4 (17%) | 2 ( 9%) |
| | *BC/BS plans-M* | 4 (14%) | 6 (21%) | 7 (24%) | 9 (31%) | 3 (10%) |
| | *BC/BS plans-U* | 7 (39%) | 3 (17%) | 2 (11%) | 4 (22%) | 2 (11%) |

[a] Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the chief underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

**Table 5-3—General Attitudes of Insurers Toward Genetic Information and Genetic Tests**

| Statement | Respondent | Agree strongly | Agree somewhat | Disagree somewhat | Disagree strongly | No response[a] |
|---|---|---|---|---|---|---|
| An insurer should have the option of determining how to use genetic information in determining risks. | *Commercials* | 19 (37%) | 19 (37%) | 9 (22%) | 3 ( 6%) | 1 ( 2%) |
| | *HMOs* | 2 ( 9%) | 15 (65%) | 4 (17%) | 0 ( 0%) | 2 ( 9%) |
| | *BC/BS plans-U*[b] | 9 (31%) | 15 (52%) | 4 (14%) | 0 ( 0%) | 1 ( 3%) |
| | *BC/BS plans-M* | 8 (44%) | 6 (33%) | 0 ( 0%) | 3 (17%) | 1 ( 6%) |
| It's fair for insurers to use genetic tests to identify individuals with increased risk of genetic disease. | *Commercials* | 11 (22%) | 23 (45%) | 11 (22%) | 4 ( 8%) | 2 ( 4%) |
| | *HMOs* | 3 (13%) | 14 (61%) | 2 ( 9%) | 2 ( 9%) | 2 ( 9%) |
| | *BC/BS plans-U* | 4 (14%) | 17 (59%) | 4 (14%) | 2 ( 7%) | 2 ( 7%) |
| | *BC/BS plans-M* | 0 ( 0%) | 11 (61%) | 2 (11%) | 4 (22%) | 1 ( 6%) |

[a]Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

tant'' or ''important,'' were personal medical history of significant conditions, family medical history of significant conditions, and carrier risk for genetic disease—although the importance respondents placed on any single factor varied. Many, in fact, considered certain factors unimportant or never used them in decisionmaking.

Overall, how do health insurers view genetic information, regardless of the source (i.e., a positive test or elevated risk for carrier status or disease because of a known family history)? Results from OTA's survey found a majority of respondents, both as an aggregate population and as individual subsets, agreed with the statement, ''Genetic information is no different than other types of medical information'' (table 5-2). Underscoring this finding are results that the majority of health insurers, collectively, agree ''strongly'' or ''somewhat'' that genetic conditions such as cystic fibrosis (CF) or Huntington disease are preexisting conditions, but that carrier status for diseases such as Tay-Sachs or CF is not a preexisting condition (table 5-2).

Third-party payors already use genetic information in making decisions about individual policies or medically underwritten groups, and health insurers clearly believe it is fair for them to have access to information known to the applicant. Survey respondents were asked whether ''an insurer should have the option of determining how to use genetic information in determining risks.'' A majority of all respondents agreed strongly or somewhat with this statement (table 5-3).

OTA also sought the reactions of commercial insurers, HMOs, and BC/BS plans to a hypothetical situation based on a real life case. Respondents were asked to indicate whether they ''agree'' strongly,''

''agree somewhat,'' ''disagree somewhat,'' or ''disagree strongly,'' with:

> Prenatal diagnosis indicates the fetus is affected with cystic fibrosis; the couple decides to continue the pregnancy. The health insurance carrier, which paid for the tests, informs the couple they will have no financial responsibility for the CF-related costs for the child.

For commercial vendors, three medical directors (6 percent) agreed strongly or somewhat. Thirteen individuals (25 percent) in this population disagreed somewhat and 34 (67 percent) disagreed strongly. Among medical directors at HMOs, 3 respondents (13 percent) agree to some extent, but 18 respondents (78 percent) disagreed, 15 (65 percent) of them strongly. For chief underwriters of BC/BS plans, six respondents agreed (21 percent), either strongly or somewhat. Eight BC/BS chief underwriters (28 percent) indicated they disagreed somewhat, and 14 (48 percent) disagreed strongly. Among medical directors of BC/BS plans, 1 (6 percent) agreed strongly, 1 (6 percent) agreed somewhat, and 15 (84 percent) disagreed strongly or somewhat.

## USE OF GENETIC TESTS

Health insurers do not *need* genetic tests to find out genetic information. Currently, it is less expensive to ask a question or request medical records, and applicants disclose genetic information as part of the battery of questions they respond to in personal and family history inquiries. OTA is unaware of any insurer who currently underwrites individual or medically underwritten groups and requires carrier or presymptomatic tests (e.g., for Huntington or adult polycystic kidney diseases) (1,2), although OTA's survey findings indicate that insurers generally believe that it is fair for them to use genetic tests to identify those at increased risk of disease, and that they should decide how to use that information in risk classification (table 5-3). Thus, what about the possibility of requiring genetic tests as a condition of coverage in the future?

Even a decade from now, OTA's survey found that the majority of respondents do not expect to require genetic tests of applicants—whether or not they have a family history of serious genetic conditions—nor do they anticipate requiring carrier assays. Requiring carrier screening as a condition of consideration for insurance is viewed as even more remote than mandating genetic assays for those who have family histories of serious disorders (table 5-4).

For example, OTA found that a minority of commercial insurers who responded believe it will be ''very likely'' (2 respondents; 4 percent) or ''somewhat likely'' (17 respondents; 33 percent) that in 10 years they will require genetic testing for applicants who have a family history of serious conditions. No BC/BS chief underwriter considered it ''very likely'' that its plan would require genetic testing in the next decade for applicants who had family histories of serious disorders. Medical directors at BC/BS plans were of a similar opinion: No medical director viewed mandatory genetic testing of applicants with family histories as very likely before the turn of the century (table 5-4).

Of medical directors at HMOs, 3 of 23 (13 percent) thought their HMO would require applicants to have a genetic test if a family history of a serious disorder existed, and 5 others (22 percent) said they considered it ''somewhat likely'' tests would be required in this manner—again, in the next 10 years. A similar distribution of responses was revealed when respondents were queried about requiring carrier tests for applicants at risk of passing on serious genetic conditions to their offspring (table 5-4).

Few respondents believe their company will require genetic tests in either 5 or 10 years, but what about optional testing? Commercial health insurers and BC/BS plans do not anticipate that optional testing or screening will be part of their company's policy in 5 or 10 years. It is interesting to note that a majority of HMO-based medical directors who responded to OTA's survey said they considered it ''very likely'' or ''somewhat'' likely that their HMO would offer optional genetic testing and carrier testing in 10 years (12 respondents; 52 percent) (table 5-4). The difference in response between the HMO population versus the commercial insurers and BC/BS plans could reflect HMOs' longer standing history with and emphasis on managed and preventive care.

Thus, over the next decade, OTA's survey indicates the vast majority of health insurers that offer individual coverage or medically underwrite groups do not anticipate requiring applicants to undergo genetic screening for disease, predisposition, or carrier status. Thus, whether or not genetic information is available to health insurers hinges on whether

**Table 5-4—Projected Use of Genetic Tests by Insurers in 5 and 10 Years**

| Question | Respondent | Very likely | Somewhat likely | Somewhat unlikely | Very unlikely | No response[a] |
|---|---|---|---|---|---|---|
| **How likely do you think it is that your company/HMO will in the next 5 years:** | | | | | | |
| Require genetic testing for applicants with family histories of serious conditions? | *Commercials* | 1 ( 2%) | 3 ( 6%) | 16 (31%) | 31 (61%) | 0 ( 0%) |
| | *HMOs* | 1 ( 4%) | 4 (17%) | 7 (39%) | 9 (39%) | 2 ( 9%) |
| | *BC/BS plans-U*[b] | 0 ( 0%) | 1 ( 3%) | 11 (38%) | 15 (52%) | 2 ( 7%) |
| | *BC/BS plans-M* | 0 ( 0%) | 2 (11%) | 5 (28%) | 10 (56%) | 1 ( 6%) |
| Require carrier tests for applicants at risk of transmitting serious genetic disease to offspring? | *Commercials* | 2 ( 4%) | 13 (25%) | 35 (69%) | 1 ( 2%) | 0 ( 0%) |
| | *HMOs* | 2 ( 9%) | 3 (13%) | 5 (22%) | 11 (48%) | 2 ( 9%) |
| | *BC/BS plans-U* | 0 ( 0%) | 1 ( 3%) | 12 (41%) | 14 (48%) | 2 ( 7%) |
| | *BC/BS plans-M* | 0 ( 0%) | 1 ( 6%) | 6 (33%) | 10 (56%) | 1 ( 6%) |
| Require genetic testing for applicants with no known risk of genetic disease? | *Commercials* | 0 ( 0%) | 0 ( 0%) | 4 ( 8%) | 47 (92%) | 0 ( 0%) |
| | *HMOs* | 1 ( 4%) | 0 ( 0%) | 2 ( 9%) | 18 (78%) | 2 ( 9%) |
| | *BC/BS plans-U* | 0 ( 0%) | 1 ( 3%) | 6 (21%) | 20 (69%) | 2 ( 7%) |
| | *BC/BS plans-M* | 0 ( 0%) | 0 ( 0%) | 3 (17%) | 14 (78%) | 1 ( 6%) |
| Offer optional genetic testing and carrier testing? | *Commercials* | 0 ( 0%) | 3 ( 6%) | 18 (35%) | 30 (59%) | 0 ( 0%) |
| | *HMOs* | 4 (17%) | 6 (26%) | 6 (26%) | 5 (22%) | 2 ( 9%) |
| | *BC/BS plans-U* | 1 ( 3%) | 5 (17%) | 9 (31%) | 12 (41%) | 2 ( 9%) |
| | *BC/BS plans-M* | 1 ( 6%) | 1 ( 6%) | 7 (39%) | 7 (39%) | 2 (11%) |
| **How likely do you think it is that your company/HMO will in the next 10 years:** | | | | | | |
| Require genetic testing for applicants with family histories of serious conditions? | *Commercials* | 2 ( 4%) | 17 (33%) | 14 (28%) | 18 (35%) | 0 ( 0%) |
| | *HMOs* | 3 (13%) | 5 (22%) | 9 (39%) | 3 (13%) | 3 (13%) |
| | *BC/BS plans-U* | 0 ( 0%) | 10 (34%) | 8 (28%) | 9 (31%) | 2 ( 7%) |
| | *BC/BS plans-M* | 0 ( 0%) | 3 (17%) | 6 (33%) | 8 (44%) | 1 ( 6%) |
| Require carrier tests for applicants at risk of transmitting serious genetic disease to offspring? | *Commercials* | 1 ( 2%) | 13 (25%) | 16 (31%) | 21 (41%) | 0 ( 0%) |
| | *HMOs* | 3 (13%) | 4 (17%) | 9 (39%) | 4 (17%) | 3 (13%) |
| | *BC/BS plans-U* | 0 ( 0%) | 9 (31%) | 9 (31%) | 9 (31%) | 2 ( 7%) |
| | *BC/BS plans-M* | 0 ( 0%) | 3 (17%) | 6 (33%) | 8 (44%) | 1 ( 6%) |
| Require genetic testing for applicants with no known risk of genetic disease? | *Commercials* | 0 ( 0%) | 4 ( 8%) | 8 (16%) | 39 (76%) | 0 ( 0%) |
| | *HMOs* | 1 ( 4%) | 0 ( 0%) | 6 (26%) | 13 (57%) | 3 (13%) |
| | *BC/BS plans-U* | 0 ( 0%) | 3 (10%) | 9 (31%) | 15 (52%) | 2 ( 7%) |
| | *BC/BS plans-M* | 0 ( 0%) | 1 ( 6%) | 3 (17%) | 13 (72%) | 1 ( 6%) |
| Offer optional genetic testing and carrier testing? | *Commercials* | 0 ( 0%) | 12 (24%) | 17 (33%) | 22 (43%) | 0 ( 0%) |
| | *HMOs* | 5 (22%) | 7 (30%) | 6 (26%) | 2 ( 9%) | 3 (13%) |
| | *BC/BS plans-U* | 3 (10%) | 10 (34%) | 5 (17%) | 9 (31%) | 2 ( 7%) |
| | *BC/BS plans-M* | 2 (11%) | 3 (16%) | 4 (22%) | 7 (39%) | 2 (11%) |

[a] Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

individuals who seek personal policies, or are part of medically underwritten groups, become aware of their genetic status because of general family history, because they have sought a genetic test because of family history, or because they have been screened in some other context (2). Even then, a majority of respondents to OTA's survey reported they thought it "somewhat unlikely" or "very unlikely" that they would be using genetic *information* for underwriting (table 5-5).

## CHAPTER 5 REFERENCES

1. Raymond, H.E., Health Insurance Association of America, Washington, DC, personal communication, December 1991.

2. U.S. Congress, Office of Technology Assessment, *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening*, OTA-BA-532 (Washington, DC: U.S. Government Printing Office, August 1992).

**Table 5-5—Projected Use of Genetic Information by Insurers in 5 and 10 Years**

| Question | Respondent | Very likely | Somewhat likely | Somewhat unlikely | Very unlikely | No response[a] |
|---|---|---|---|---|---|---|
| **How likely do you think it is that your company/HMO will in the next 5 years:** | | | | | | |
| Use information derived from genetic tests for underwriting? | *Commercials* | 7 (14%) | 12 (24%) | 16 (31%) | 16 (31%) | 0 ( 0%) |
| | *HMOs* | 1 ( 4%) | 5 (22%) | 9 (26%) | 6 (26%) | 2 ( 9%) |
| | *BC/BS plans-U*[b] | 3 (10%) | 8 (28%) | 10 (34%) | 6 (21%) | 2 ( 7%) |
| | *BC/BS plans-M* | 1 ( 6%) | 2 (11%) | 7 (39%) | 7 (39%) | 1 ( 6%) |
| **In the next 10 years:** | | | | | | |
| Use information derived from genetic tests for underwriting? | *Commercials* | 12 (24%) | 20 (39%) | 11 (22%) | 7 (14%) | 1 ( 2%) |
| | *HMOs* | 3 (13%) | 6 (26%) | 8 (35%) | 3 (13%) | 3 (13%) |
| | *BC/BS plans-U* | 5 (17%) | 13 (45%) | 3 (10%) | 6 (21%) | 2 ( 7%) |
| | *BC/BS plans-M* | 1 ( 6%) | 5 (28%) | 6 (33%) | 5 (28%) | 1 ( 6%) |

[a] Percentages may not add to 100 due to rounding.
[b]BC/BS plans-U represents the underwriter population and BC/BS plans-M, the medical director population.

SOURCE: Office of Technology Assessment, 1992.

# Appendix A
# Survey Method

OTA conducted and managed all aspects of the survey, with input and advice on the survey instrument and study design from a contractor, industry officials, the Advisory Panel, and workshop participants.

## *Study Design*

The OTA survey of health insurers was conducted by mail from June 21 to September 29, 1991. The general approach was similar to a 1987 survey OTA conducted for the report *Medical Testing and Health Insurance* (4,5), although the target population differed slightly, as did the method of ensuring anonymity and confidentiality.

### Survey Populations

The overall survey population derived from three sources. The commercial health insurer population was obtained from a Health Insurance Association of America (HIAA) list of member companies that offer policies to either individuals or medically underwritten groups. The Blue Cross and Blue Shield (BC/BS) survey population was derived from the BC/BS Association's directory (1), and the health maintenance organization (HMO) population was derived from the Group Health Association of America (GHAA) 1991 National Directory of HMOs (2).

For the commercial insurers, OTA sent a copy of the survey and an HIAA letter of endorsement to medical directors of the 225 commercial health insurers identified by HIAA as those that offered either individual or medically underwritten group coverage. The list OTA obtained was 4 years old and in that time well over half of those companies had stopped offering individual coverage (3). The reported response rate for commercial insurers reflects those repondents who returned surveys stating they did not offer either type of coverage, but makes no adjustment for nonrespondents who might also not offer such coverage.

Both the chief underwriter and the chief medical director at 72 of 73 BC/BS plans (Puerto Rico was excluded) were sent surveys; a letter of endorsement from the national BC/BS Association also accompanied this survey. Finally, OTA sent surveys to medical directors at the 50 largest HMOs, as well as to an additional 28 plans that were not among the 50 largest U.S. plans, but were the largest HMO within a State or the largest by HMO model type. (Four HMO model types exist: the staff, group, network, and independent practice association model plans.)

A followup letter was mailed to those whose replies were not received within 3 weeks of the first mailing.

### Questionnaire Development

Three separate survey questionnaires were developed to account for slight variations in the types of products each population offers, but the substance of the questions was the same (app. C). The instruments contained some items comparable to the 1987 OTA survey performed for *Medical Testing and Health Insurance* (4). Representatives of HIAA, BC/BS Association, and GHAA reviewed multiple drafts of the questionnaires and provided input on industry practices.

### Confidentiality

A respondent identification number was placed on the last page of each questionnaire. This permitted improved sample tracking and allowed identification of duplicate returns. The numbered sticker was affixed using a peel-off label that could be removed by respondents who wished to remain anonymous. Respondents were encouraged to leave the peel-off label on the survey and informed that it would be removed after receipt. After OTA received the questionnaires, the peel-off labels were removed, making the data both anonymous and confidential.

## *Sample Disposition*

Fifty-one commercial insurers that underwrite individual or medically underwritten groups responded. An additional 81 commercial insurance companies responded that they no longer wrote either type of policy. The overall response rate among the 225 organizations was 59 percent. Of the 72 BC/BS surveys sent out, 29 chief underwriters completed a survey (40 percent response rate), as did 18 chief medical directors (25 percent response rate). Of the 78 surveys sent to HMOs, 43 surveys were returned (55 percent response rate); 20 of these respondents offered neither individual nor medically underwritten groups.

## *Appendix A References*


1. Blue Cross and Blue Shield Association Directory (Chicago, IL: Blue Cross and Blue Shield Association, 1990).
2. Group Health Association of America, *1991 National Directory* (Washington, DC: GHAA, 1991).
3. Raymond, H., Health Insurance Association of America, Washington DC, personal communication, December 1991.

4. U.S. Congress, Office of Technology Assessment, *AIDS and Health Insurance—An OTA Survey*, NTIS PB88-170204 (Springfield, VA: National Technical Information Service, February 1988).
5. U.S. Congress, Office of Technology Assessment, *Medical Testing and Health Insurance*, OTA-H-384 (Washington, DC: U.S. Government Printing Office, August 1988).

# Appendix B
# Qualitative Comments From the Survey

Space was provided at the end of the questionnaire for any general comments a respondent wished to make. Additionally, several respondents wrote opinions, concerns, and suggestions related to an item in the margin. These open-ended comments of the survey participants provide additional detail and context on current attitudes and concerns among health insurers about genetic tests and genetic information. Where necessary for clarification, bracketed text has been added by OTA.

## *Commercial Health Insurers*

1. So far so good. As long as no one [i.e., other insurance companies] is testing we are not at risk beyond that contemplated by our rate structure. As soon as genetic predisposition is employed on a widespread basis we will be forced to follow suit.
2. We currently do not employ genetic testing for underwriting. However, if it ever becomes a nationally accepted policy, we would utilize it judiciously in order to remain competitive.
3. Genetic testing should be on a level playing field (i.e., applicants and insurers should have equal access to the same information to prevent antiselection).
4. Considering the thousands of other significant medical impairments insurance companies must contend with, the incidence of genetically transmitted disease is a relatively insignificant matter!
5. Individuals with genetic impairments should not be excluded from health coverage. Federally subsidized plans may be needed to supplement what is available from commercial carriers.
6. Required genetic testing to obtain health insurance in general will not be beneficial to applicants for health insurance or to insurance companies. Rated group premiums should be adequate in most cases to compensate for extra risk. If an applicant at high risk to serious genetic disease submits genetic test results on his own which are favorable, then group premium can be adjusted appropriately downward.
7. Our company has more than 1 million health insurance policies in force for individuals and families. The great majority of these are guarantee-issue hospital indemnity policies with waiting periods (ordinarily 1 year) for preexisting conditions. For this part of our business, every applicant is eligible at standard rates. I completed the questionnaire as it pertained to a much smaller segment of our business. This is a medically underwritten, hospital-medical-surgical policy with a lifetime aggregate benefit, in most instances, of 1 million dollars. We will receive about 36,000 applications for this kind of policy in '91. Underwriting is performed from the application and APS [attending physician statement] information. We do not use paramedical exams or tests, and have no plans for genetic testing. We are not an MIB member [Medical Information Bureau, Inc.] .
8. If possibility of future disease is 100 percent from testing we might consider using info for underwriting. If it is only a lesser probability, then I doubt if we could use that info.
9. Although incremental in its effect on indemnity industry, the genetic testing referenced will ultimately expand to numerous additional conditions. A broad view of insurance industry cost/risk should be taken from the inception to provide satisfactory protection from additional burden to the premium paying public.
10. This questionnaire appears to me to be poorly conceived and executed; many of the questions appear to be unfairly loaded or betray an ignorance of customary health insurance underwriting practices. Genetic testing is an important societal issue, and intellectually flawed and/or politically motivated exercises seem unlikely to advance the public good in this, or any other, area.
11. This survey appears entirely premature. The insurance industry is not considering screening for genetic diseases. No testing is available yet that is practical. We just want to underwrite symptomatic genetic conditions just like everything else.
12. As an insurer, we are not anxious to begin testing for underwriting purposes; however, if an applicant has already taken the test, it is *critically important* that we have the opportunity to access the test results.
13. We have no plans to perform genetic tests on our applicants. If, however, a genetic test has been done it is extremely important that we know what the applicant knows about his or her own condition. Adverse selection against any one company could jeopardize its financial status and ability to pay future claims.
14. This was a lot of information you requested to be answered in a relatively short period of time!

## *Blue Cross and Blue Shield Plans*

1. Our answer regarding coverage of persons or families at risk for serious genetic disorders is predicated on

our State-mandated requirement to offer some type of coverage to all applicants.

2. Not all questions were completed since we currently do not require testing of any kind or family history information in our medical underwriting process. We do not specifically inquire on the application for coverage about genetic conditions listed in the survey. However, applicants with these known conditions are not considered standard risks and would be declined coverage with our company. Payment for some genetic testing is covered under some of our health insurance policies depending on the diagnosis and if the services are determined to be medically necessary.
3. The responses are a result of our "Corporate Medical Policy Committees" input. Our corporation is nonprofit and is founded on a social/community mission and responsibility. Therefore, we accept all applicants. Due to fiscal difficulties, we are *considering implementing* a waiting period of one year even in our group business. We will still accept all but apply the waiting period.
4. Our position on treatment of genetic testing and applying such information in our underwriting practices will be directly affected by the position of the other insurers. This is necessary to assure that adverse selection is avoided.
5. While I do not support insurer-required genetic testing, I feel insurers must be permitted to use applicant-initiated testing results on the same basis as other medical information.
6. Currently we rider individuals with certain conditions. In 1992, we plan to stop "ridering" and begin "risk adjusting premiums." At that time, we will become much more concerned about genetic disorders. However, we do not anticipate requiring genetic testing.
7. This survey was answered with 1990 statistics; it excludes LTC [long-term care] as a line of business. The only "open enrollment" for individual plan members is limited to noneligible group members; Hawaii does not medically underwrite groups.
8. The questions asked do not take a number of factors into account (i.e., it is not stated if currently covered, requesting coverage, are symptoms and treatment currently being rendered, etc.)
9. Our underwriting practices and decisions are highly regulated by the State Department of Insurance, which severely limits our ability to consistently apply sound and equitable risk evaluation techniques.
10. The public should demand that health insurers and employers follow their earlier mission of spreading risk, rather than avoiding risk. Additionally, coverage for genetic testing should be provided if medically necessary; criteria which probably need to be refined. If my responses seem confusing, be aware that we ask for medical histories from nongroup applicants [as a method of collecting data], but we are resolute in neither denying coverage nor rating surcharges for high risk individuals. Of course, we don't make a lot of profit with these practices.

### *Health Maintenance Organizations*

1. As an IPA-fee-for-service [independent practice association] HMO in our State, we can not exclude preexisting conditions. Therefore, we are at a distinct disadvantage with other competitors in the field who are permitted such an approach. We therefore are always experiencing adverse selection and show hemophiliacs, AIDS patients, etc.—far in excess of random population statistics.

# Appendix C
# Survey Instruments

As part of the 1992 assessment *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening*, OTA surveyed commercial health insurers that offer policies to individuals or medically underwritten groups, Blue Cross and Blue Shield plans, and selected health maintenance organizations. The instruments were tailored slightly for each population, but the substance for all three questionnaires was unchanged. The following are reproductions of the survey questionnaires. For Blue Cross and Blue Shield plans, identical surveys were sent separately to chief underwriters and medical directors, but only the former is reproduced.

## CONGRESSIONAL OFFICE OF TECHNOLOGY ASSESSMENT

### SURVEY OF HEALTH INSURERS' ATTITUDES AND PRACTICES REGARDING GENETIC TESTING FOR CYSTIC FIBROSIS

ATTN: MEDICAL DIRECTOR

Please Respond by July 15, 1991

The Congressional Office of Technology Assessment (OTA) is contacting health insurers who offer individual coverage in a national survey of attitudes and practices regarding cystic fibrosis screening. This questionnaire has been directed to you as the person in your organization whose responsibilities include medical decisionmaking. We request your assistance in answering some questions about genetic testing and medical decisionmaking in your company. **If you are not the Medical Director, we would appreciate it if you would please forward the questionnaire to the appropriate person.**

For the purposes of this survey, OTA has adopted the following definitions:

> By *carrier testing*, we mean testing an unaffected individual to reveal the possibility that off-spring may have a serious chronic condition or disease (e.g., cystic fibrosis or sickle cell disease).
>
> By *genetic testing*, we mean testing applicants or policyholders for certain inherited characteristics either presymptomatically to reveal future serious chronic disease (e.g., for Huntington's disease) or for risk oriented purposes (e.g., predisposition to heart disease).

This is an important study that has been requested by the U.S. Congress, and is designed to represent the attitudes and practices of health insurers. We need to know how insurers view the technologies of genetic testing in terms of their current and future applications in health insurance.

Please read each question and mark the space that most nearly corresponds to your answer. Please feel free to qualify your answers. Space has been provided at the end for comments and opinions that you feel are not adequately represented by the survey questions. The survey responses will be kept strictly anonymous as well as confidential.

**PLEASE NOTE:** This survey focuses on two health insurance populations---(1) *Individuals* who seek insurance independently and without any association with an employer or membership group of any kind; and (2) *Medically underwritten groups*, i.e., those groups whose members must be medically underwritten.

**********

*Conversions should be excluded from your responses.* In addition, we prefer that you exclude Medigap insurance from your responses. If because of reporting or other reasons, you must include Medigap policies, please check the box below:

[ ] YES, Medigap policies and statistics are included in our responses to this survey.

Do you offer coverage for either individuals or medically underwritten groups?

Yes _____ (1)
No _____ (2)

IF YOU ARE NOT OFFERING EITHER OF THESE TYPES OF COVERAGE, THIS COMPLETES YOUR SURVEY. THANK YOU VERY MUCH. PLEASE RETURN IT IN THE PRE-ADDRESSED POST-PAID ENVELOPE.

SECTION I: INDIVIDUAL AND GROUP STATISTICS

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| 1. What is the approximate number of persons that you currently insure through: | _____ | _____ |
| 2. What is the approximate number of applications received by your company per year for coverage under: | _____ | _____ |
| 3. What portion of those applications are: | | |
| a. Accepted at standard rates | _____% | _____% |
| b. Covered with an exclusion waiver, but standard premium | _____% | _____% |
| c. Covered with a rated premium, but not exclusion waiver | _____% | _____% |
| d. Covered with an exclusion waiver and a rated premium | _____% | _____% |
| e. Declined by your company | _____% | _____% |
| f. Other (SPECIFY) | _____% | _____% |
| _____ | _____% | _____% |
| _____ | _____% | _____% |
| TOTAL | 100% | 100% |

**SECTION II: UNDERWRITING PRACTICES**

4. For each category of coverage, please estimate the proportion of all health insurance applicants from whom you require:

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| a. A personal health history | _____% | _____% |
| b. A family health history | _____% | _____% |

IF A FAMILY HISTORY IS REQUIRED, ON WHOM WOULD INFORMATION BE REQUESTED. CHECK ALL THAT APPLY.

[ ] Spouse (1)
[ ] Parents (2)
[ ] Grandparents (3)
[ ] Siblings (4)
[ ] Children (5)
[ ] Other (SPECIFY) _____ (6)

| | | |
|---|---|---|
| c. An attending physician statement (APS) | _____% | _____% |

IF AN APS IS REQUIRED FOR ANY INDIVIDUALS, WHICH OF THE FOLLOWING WOULD TRIGGER THE REQUIREMENT. CHECK ALL THAT APPLY.

[ ] Any significant diagnosis or symptoms reported on application (1)
[ ] Selected diagnoses or symptoms reported on application (2)
[ ] Any significant conditions reported in family history (3)
[ ] Selected conditions reported in family history (4)
[ ] M.I.B. report (5)

| | | |
|---|---|---|
| d. Physical exam: | _____% | _____% |

IF AN EXAM IS EVER REQUIRED, WHICH OF THE FOLLOWING WOULD TRIGGER THE REQUIREMENT. CHECK ALL THAT APPLY.

[ ] Any significant diagnosis or symptoms reported on application (1)
[ ] Selected diagnoses or symptoms reported on application (2)
[ ] Any significant conditions reported in family history (3)
[ ] Selected conditions reported in family history (4)
[ ] M.I.B. report (5)
[ ] Any significant diagnosis or symptoms identified in APS (6)

| | | |
|---|---|---|
| e. Blood or urine screens: | _____% | _____% |

5. For each category of coverage, please indicate the importance of each of the following factors in determining insurability (not in rating):

*1 = Very important; 2 = Important; 3 = Unimportant; 4 = Never used*

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| a. Age | _____ | _____ |
| b. Occupation | _____ | _____ |
| c. Smoking status | _____ | _____ |
| d. Lifestyle | _____ | _____ |
| e. Sex | _____ | _____ |
| f. Financial/credit status | _____ | _____ |
| g. Personal medical history of significant conditions | _____ | _____ |
| h. Family medical history of significant conditions | _____ | _____ |
| i. Genetic predisposition to significant conditions | _____ | _____ |
| j. Carrier risk for genetic diseases | _____ | _____ |

6. How would you normally treat either an individual policy applicant or medically underwritten groups that disclosed the following conditions in an examination(s) or application:

*1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;*
*3 = Accepted with exclusion waiver at rated premium;*
*4 = Accepted without exclusion waiver but at rated premium; 5 = Declined*

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| a. Hypertension | _____ | _____ |
| b. Diabetes mellitus | _____ | _____ |
| c. Cerebrovascular disease | _____ | _____ |
| d. Hemophilia | _____ | _____ |
| e. Cystic fibrosis | _____ | _____ |
| f. Sickle cell anemia | _____ | _____ |

## SECTION III: GENETIC CONDITIONS

7. Does your company specifically inquire, for each category of coverage, about the following conditions in the application for health insurance in the personal history, family history, or neither:

*1 = Personal history only; 2 = Family history; 3 = Neither*

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| a. Hemophilia | _____ | _____ |
| b. Tay-Sachs | _____ | _____ |
| c. Huntington's disease | _____ | _____ |
| d. Sickle cell anemia | _____ | _____ |
| e. Cystic fibrosis | _____ | _____ |
| f. Any other genetic disease (SPECIFY) | _____ | _____ |

8. For individual policy applicants only, how would the application normally be treated if a policy applicant was asymptomatic but had a family history of:

*1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;*
*3 = Accepted with exclusion waiver at rated premium;*
*4 = Accepted without exclusion waiver but at rated premium; 5 = Declined*

| | Individual Policies |
|---|---|
| a. Hemophilia | _____ |
| b. Tay-Sachs | _____ |
| c. Huntington's disease | _____ |
| d. Sickle cell anemia | _____ |
| e. Cystic fibrosis | _____ |
| f. Duchenne muscular dystrophy | _____ |
| g. ADA deficiency ("Bubble Boy disease") | _____ |
| h. Down Syndrome | _____ |

9. For individual policy applicants only, how would the coverage of a family member (e.g., spouse or adopted child) be affected if the policy applicant was negative, but the family member was asymptomatic but had a family history of:

*1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;*
*3 = Accepted with exclusion waiver at rated premium;*
*4 = Accepted without exclusion waiver but at rated premium; 5 = Declined*

| | Individual Policies |
|---|---|
| a. Hemophilia | _____ |
| b. Tay-Sachs | _____ |
| c. Huntington's disease | _____ |
| d. Sickle cell anemia | _____ |
| e. Cystic fibrosis | _____ |
| f. Duchenne muscular dystrophy | _____ |
| g. ADA deficiency ("Bubble Boy disease") | _____ |
| h. Down Syndrome | _____ |

10. Do your standard individual policies and medically underwritten policies provide coverage for:

*1 = At patient request; 2 = Only if medically indicated; 3 = Not covered*

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| Carrier tests for: | | |
| a. Cystic fibrosis | _____ | _____ |
| b. Tay-Sachs | _____ | _____ |
| c. Sickle cell trait | _____ | _____ |
| Prenatal tests for: | | |
| d. Cystic fibrosis | _____ | _____ |
| e. Tay-Sachs | _____ | _____ |
| f. Sickle cell anemia | _____ | _____ |
| g. Down Syndrome | _____ | _____ |
| h. Other (SPECIFY) | _____ | _____ |
| Genetic counseling | _____ | _____ |

11. How would individual policies and medically underwritten policies normally be affected by the following findings:

*1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;*
*3 = Accepted with exclusion waiver at rated premium;*
*4 = Accepted without exclusion waiver but at rated premium; 5 = Declined*

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| a. Presymptomatic testing reveals the likelihood of a serious, chronic future disease (e.g., for Huntington's disease) | _____ | _____ |
| b. Risk oriented testing reveals that an individual carries markers associated with a serious, chronic future disease (e.g., predisposition to heart disease) | _____ | _____ |
| c. Carrier testing reveals the possibility that off-spring may have a serious, chronic condition or disease | _____ | _____ |
| d. Prenatal diagnosis reveals fetus affected with a serious, chronic condition or disease | _____ | _____ |

## SECTION IV: GENERAL ATTITUDES

12. To your knowledge, has your company ever reimbursed for carrier testing for cystic fibrosis?
Yes _____(1)
No _____(2)

13. Has your company ever conducted an economic analysis of the costs and benefits of:

| | Yes | No |
|---|---|---|
| a. Carrier testing as part of applicant screening | 1 | 2 |
| b. Genetic counseling of carriers who are covered | 1 | 2 |
| c. Carrier testing as part of prenatal coverage | 1 | 2 |
| d. Genetic testing as part of applicant screening | 1 | 2 |

14. Under what conditions would a negative financial impact be likely to occur for your company: (CHECK ALL THAT APPLY)

a. Widespread availability of genetic tests to the medical/provider community _____(1)
b. Widespread availability of genetic tests with constraints on insurers' access to the results _____(2)
c. Adverse claims or underwriting results from antiselection _____(3)
d. Other (SPECIFY) _____ (4)

15. How likely do you think it is that your company will:

| | Very Likely | Somewhat Likely | Somewhat Unlikely | Very Unlikely |
|---|---|---|---|---|
| In the next 5 years: | | | | |
| a. Require genetic testing for applicants with family histories of serious conditions | 1 | 2 | 3 | 4 |
| b. Require carrier tests for applicants at risk of transmitting serious genetic diseases to offspring | 1 | 2 | 3 | 4 |
| c. Require genetic testing for applicants with no known risk to genetic disease | 1 | 2 | 3 | 4 |
| d. Offer optional genetic testing and carrier testing | 1 | 2 | 3 | 4 |
| e. Use information derived from genetic tests for underwriting | 1 | 2 | 3 | 4 |
| f. Alter claims payment practices as new genetic tests come on line | 1 | 2 | 3 | 4 |
| In the next 10 years: | | | | |
| g. Require genetic testing for applicants with family histories of serious conditions | 1 | 2 | 3 | 4 |
| h. Require carrier tests for applicants at risk of transmitting serious genetic diseases to offspring | 1 | 2 | 3 | 4 |
| i. Require genetic testing for applicants with no known risk to genetic disease | 1 | 2 | 3 | 4 |
| j. Offer optional genetic testing and carrier testing | 1 | 2 | 3 | 4 |
| k. Use information derived from genetic tests for underwriting | 1 | 2 | 3 | 4 |
| l. Alter claims payment practices as new genetic tests come on line | 1 | 2 | 3 | 4 |

16. Please indicate whether you:

| | Agree Strongly | Agree Somewhat | Disagree Somewhat | Disagree Strongly |
|---|---|---|---|---|
| a. It's fair for insurers to use genetic tests to identify individuals with increased risk of disease. | 1 | 2 | 3 | 4 |
| b. An insurer should have the option of determining how to use genetic information in determining risks. | 1 | 2 | 3 | 4 |
| c. Genetic conditions, such as cystic fibrosis or Huntington's disease, are pre-existing conditions. | 1 | 2 | 3 | 4 |
| d. Carrier status for genetic conditions, such as cystic fibrosis or Tay-Sachs, are pre-existing conditions. | 1 | 2 | 3 | 4 |
| e. Genetic information is no different than other types of medical information. | 1 | 2 | 3 | 4 |
| f. Prenatal diagnosis indicates the fetus is affected with cystic fibrosis; the couple decide to continue the pregnancy. The health insurance carrier, which paid for the tests, informs the couple they will have no financial responsibility for the cystic fibrosis-related costs for the child. | 1 | 2 | 3 | 4 |
| g. Through prior genetic testing, the husband is known to be a carrier for cystic fibrosis. Before having children, the wife seeks genetic testing for cystic fibrosis. The insurance company declines to pay for the testing, since there is no history of cystic fibrosis in her family. | 1 | 2 | 3 | 4 |

**SECTION V: DEMOGRAPHICS**

17. What is your job title?

_____

18. Which of the following lines of insurance does your company underwrite?

| | |
|---|---|
| Health | 1 |
| Disability | 2 |
| Life | 3 |

19. What percent of persons under health insurance policies issued by your company are in policies classified as:

| | |
|---|---|
| Self-insured Administration | _____% |
| Individual | _____% |
| Medically Underwritten Groups | _____% |
| Large Groups | _____% |
| TOTAL | 100% |

Thank you very much for your cooperation in answering our questions. We would also like to give you an opportunity to give us as any other opinions, concerns, or suggestions related to genetic testing and insurance that you feel our questions did not address. These comments will be strictly anonymous but may be incorporated in our report to Congress. Please write these comments below.

_____

_____

_____

_____

_____

_____

We have attached a peel-off identification number on the questionnaire. This is the only link between the companies who were sampled and the questionnaires returned. We would prefer that you leave the identification number on the questionnaire when you return it. Our staff will remove the label upon receipt, making the questionnaire entirely anonymous. Absolutely no linkage between companies and questionnaires will be retained. The label from the completed questionnaire is designed to eliminate your company from those that we will have to recontact.

However, if this temporary identification makes you uncomfortable, then peel off the label before returning the questionnaire. We appreciate your help and we want you to feel comfortable in participating in the survey.

_____

PEEL OFF LABEL WITH SAMPLE

IDENTIFICATION HERE

_____

PLEASE RETURN THE QUESTIONNAIRE IN THE POSTAGE PAID RETURN ENVELOPE SENT WITH THE QUESTIONNAIRE. IF THE ENVELOPE HAS BEEN LOST, THE RETURN ADDRESS IS:

Margaret Anderson
Biological Applications Program
Office of Technology Assessment
U.S. Congress
Washington, DC 20510-8025

## CONGRESSIONAL OFFICE OF TECHNOLOGY ASSESSMENT

### SURVEY OF HMOs' ATTITUDES AND PRACTICES REGARDING GENETIC TESTING FOR CYSTIC FIBROSIS

**ATTN: MEDICAL DIRECTOR**

**Please Respond by July 19, 1991**

The Congressional Office of Technology Assessment (OTA) is contacting health insurers and HMOs who offer individual coverage in a national survey of attitudes and practices regarding cystic fibrosis screening. This questionnaire has been directed to you as the person in your organization whose responsibilities include medical decisionmaking. We request your assistance in answering some questions about genetic testing and medical decisionmaking in your company. **If you are not the Medical Director, we would appreciate it if you would please forward the questionnaire to the appropriate person.**

For the purposes of this survey, OTA has adopted the following definitions:

> By *carrier testing*, we mean testing an unaffected individual to reveal the possibility that off-spring may have a serious chronic condition or disease (e.g., cystic fibrosis or sickle cell disease).
>
> By *genetic testing*, we mean testing applicants or policyholders for certain inherited characteristics either presymptomatically to reveal future serious chronic disease (e.g., for Huntington's disease) or for risk oriented purposes (e.g., predisposition to heart disease).

This is an important study that has been requested by the U.S. Congress, and is designed to represent the attitudes and practices of health insurers and HMOs. We need to know how insurers view the technologies of genetic testing in terms of their current and future applications in health insurance.

Please read each question and mark the space that most nearly corresponds to your answer. Please feel free to qualify your answers. Space has been provided at the end for comments and opinions that you feel are not adequately represented by the survey questions. The survey responses will be kept strictly anonymous as well as confidential.

**PLEASE NOTE:** This survey focuses on two HMO populations–(1) *Individuals*, non-conversion self-payers who seek HMO membership independently and without any association with an employer or membership group of any kind; and (2) *Medically underwritten groups*, i.e., those groups whose members must be medically underwritten.

**********

*Conversions should be excluded from your responses.* In addition, we prefer that you exclude applicants for supplemental Medicare coverage from your responses. If because of reporting or other reasons, you must include Medicare policies, please check the box below:

[ ] YES, Medicare policies and statistics are included in our responses to this survey.

SECTION I: BACKGROUND

1. Do you offer coverage for either self-paying individuals (other than on a conversion basis) or medically underwritten groups?

   Yes _____(1)
   No _____(2)

IF YOU ARE NOT OFFERING EITHER OF THESE TYPES OF COVERAGE, THIS COMPLETES YOUR SURVEY. THANK YOU VERY MUCH. PLEASE RETURN IT IN THE PRE-ADDRESSED POSTAGE-PAID ENVELOPE.

2. Is your plan federally qualified? [ ] Yes (1) [ ] No (2)

   If no, is Federal qualification pending? [ ] Yes (1) [ ] No (2)

   If yes, do you have a non-federally qualified subsidiary? [ ] Yes (1) [ ] No (2)

3. Does your plan have an open enrollment period (i.e., no medical screening) for self-payers?

   [ ] Yes (1) [ ] No (2)

   If yes, is it continuous? [ ] Yes (1) [ ] No (2)

4. Which model type is your plan? Check all that apply, but if more than one type is offered, indicate which is primary, secondary, etc. by the number of patients covered.

   Staff Model Plan _____

   Group Model Plan _____

   Network Model Plan _____

   IPA Model Plan _____

**SECTION II: INDIVIDUAL AND GROUP STATISTICS**

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| 5. What is the approximate number of persons that you currently insure through: | _____ | _____ |
| 6. What is the approximate number of applications received by your company per year for coverage under: | _____ | _____ |
| 7. What portion of those applications are: | | |
| a. Accepted at standard rates | _____% | _____% |
| b. Covered with an exclusion waiver, but standard premium | _____% | _____% |
| c. Covered with a rated premium, but not exclusion waiver | _____% | _____% |
| d. Covered with an exclusion waiver and a rated premium | _____% | _____% |
| e. Declined by your company | _____% | _____% |
| f. Other (SPECIFY) | _____% | _____% |
| _____ | _____% | _____% |
| _____ | _____% | _____% |
| TOTAL | 100% | 100% |

SECTION III: UNDERWRITING PRACTICES

8. For each category of coverage, please estimate the proportion of all HMO applicants from whom you require:

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| a. A personal health history | _____% | _____% |
| b. A family health history | _____% | _____% |

IF A FAMILY HISTORY IS REQUIRED, ON WHOM WOULD INFORMATION BE REQUESTED. CHECK ALL THAT APPLY.

[ ] Spouse (1)
[ ] Parents (2)
[ ] Grandparents (3)
[ ] Siblings (4)
[ ] Children (5)
[ ] Other (SPECIFY) _____ (6)

| | | |
|---|---|---|
| c. An attending physician statement (APS) | _____% | _____% |

IF AN APS IS REQUIRED FOR ANY INDIVIDUALS, WHICH OF THE FOLLOWING WOULD TRIGGER THE REQUIREMENT. CHECK ALL THAT APPLY.

[ ] Any significant diagnosis or symptoms reported on application (1)
[ ] Selected diagnoses or symptoms reported on application (2)
[ ] Any significant conditions reported in family history (3)
[ ] Selected conditions reported in family history (4)
[ ] M.I.B. report (5)

| | | |
|---|---|---|
| d. Physical exam: | _____% | _____% |

IF AN EXAM IS EVER REQUIRED, WHICH OF THE FOLLOWING WOULD TRIGGER THE REQUIREMENT. CHECK ALL THAT APPLY.

[ ] Any significant diagnosis or symptoms reported on application (1)
[ ] Selected diagnoses or symptoms reported on application (2)
[ ] Any significant conditions reported in family history (3)
[ ] Selected conditions reported in family history (4)
[ ] M.I.B. report (5)
[ ] Any significant diagnosis or symptoms identified in APS (6)

| | | |
|---|---|---|
| e. Blood or urine screens: | _____% | _____% |

9. For each category of coverage, please indicate the importance of each of the following factors in determining insurability (not in rating):

*1 = Very important; 2 = Important; 3 = Unimportant; 4 = Never used*

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| a. Age | _____ | _____ |
| b. Occupation | _____ | _____ |
| c. Smoking status | _____ | _____ |
| d. Lifestyle | _____ | _____ |
| e. Sex | _____ | _____ |
| f. Financial/credit status | _____ | _____ |
| g. Personal medical history of significant conditions | _____ | _____ |
| h. Family medical history of significant conditions | _____ | _____ |
| i. Genetic predisposition to significant conditions | _____ | _____ |
| j. Carrier risk for genetic diseases | _____ | _____ |

10. How would you normally treat either an individual policy applicant or medically underwritten groups that disclosed the following conditions in an examination(s) or application:

*1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;*
*3 = Accepted with exclusion waiver at rated premium;*
*4 = Accepted without exclusion waiver but at rated premium; 5 = Declined*

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| a. Hypertension | _____ | _____ |
| b. Diabetes mellitus | _____ | _____ |
| c. Cerebrovascular disease | _____ | _____ |
| d. Hemophilia | _____ | _____ |
| e. Cystic fibrosis | _____ | _____ |
| f. Sickle cell anemia | _____ | _____ |

SECTION IV: GENETIC CONDITIONS

11. Does your company specifically inquire, for each category of coverage, about the following conditions in the HMO application in the personal history, family history, or neither:

*1 = Personal history only; 2 = Family history; 3 = Neither*

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| a. Hemophilia | _____ | _____ |
| b. Tay-Sachs | _____ | _____ |
| c. Huntington's disease | _____ | _____ |
| d. Sickle cell anemia | _____ | _____ |
| e. Cystic fibrosis | _____ | _____ |
| f. Any other genetic disease (SPECIFY) | _____ | _____ |

12. For individual policy applicants only, how would the application normally be treated if a policy applicant was asymptomatic but had a family history of:

*1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;*
*3 = Accepted with exclusion waiver at rated premium;*
*4 = Accepted without exclusion waiver but at rated premium; 5 = Declined*

| | Individual Policies |
|---|---|
| a. Hemophilia | _____ |
| b. Tay-Sachs | _____ |
| c. Huntington's disease | _____ |
| d. Sickle cell anemia | _____ |
| e. Cystic fibrosis | _____ |
| f. Duchenne muscular dystrophy | _____ |
| g. ADA deficiency ("Bubble Boy disease") | _____ |
| h. Down Syndrome | _____ |

13. For individual policy applicants only, how would the coverage of a family member (e.g., spouse or adopted child) be affected if the policy applicant was negative, but the family member was asymptomatic but had a family history of:

*1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;*
*3 = Accepted with exclusion waiver at rated premium;*
*4 = Accepted without exclusion waiver but at rated premium; 5 = Declined*

| | Individual Policies |
|---|---|
| a. Hemophilia | _____ |
| b. Tay-Sachs | _____ |
| c. Huntington's disease | _____ |
| d. Sickle cell anemia | _____ |
| e. Cystic fibrosis | _____ |
| f. Duchenne muscular dystrophy | _____ |
| g. ADA deficiency ("Bubble Boy disease") | _____ |
| h. Down Syndrome | _____ |

14. Do your standard individual policies and medically underwritten policies provide coverage for:

*1 = At patient request; 2 = Only if medically indicated; 3 = Not covered*

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| Carrier tests for: | | |
| a. Cystic fibrosis | _____ | _____ |
| b. Tay-Sachs | _____ | _____ |
| c. Sickle cell trait | _____ | _____ |
| Prenatal tests for: | | |
| d. Cystic fibrosis | _____ | _____ |
| e. Tay-Sachs | _____ | _____ |
| f. Sickle cell anemia | _____ | _____ |
| g. Down Syndrome | _____ | _____ |
| h. Other (SPECIFY) | _____ | _____ |
| Genetic counseling | _____ | _____ |

15. How would individual policies and medically underwritten policies normally be affected by the following findings:

*1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;*
*3 = Accepted with exclusion waiver at rated premium;*
*4 = Accepted without exclusion waiver but at rated premium; 5 = Declined*

| | Individual Policies | Medically Underwritten Groups |
|---|---|---|
| a. Presymptomatic testing reveals the likelihood of a serious, chronic future disease (e.g., for Huntington's disease) | _____ | _____ |
| b. Risk oriented testing reveals that an individual carries markers associated with a serious, chronic future disease (e.g., predisposition to heart disease) | _____ | _____ |
| c. Carrier testing reveals the possibility that off-spring may have a serious, chronic condition or disease | _____ | _____ |
| d. Prenatal diagnosis reveals fetus affected with a serious, chronic condition or disease | _____ | _____ |

## SECTION V: GENERAL ATTITUDES

16. To your knowledge, has your company ever reimbursed for carrier testing for cystic fibrosis?
Yes _____(1)
No _____(2)

17. Has your company ever conducted an economic analysis of the costs and benefits of:

| | Yes | No |
|---|---|---|
| a. Carrier testing as part of applicant screening | 1 | 2 |
| b. Genetic counseling of carriers who are covered | 1 | 2 |
| c. Carrier testing as part of prenatal coverage | 1 | 2 |
| d. Genetic testing as part of applicant screening | 1 | 2 |

18. Under what conditions would a negative financial impact be likely to occur for your company: (CHECK ALL THAT APPLY)

a. Widespread availability of genetic tests to the medical/provider community _____(1)
b. Widespread availability of genetic tests with constraints on HMOs' access to the results _____(2)
c. Adverse claims or underwriting results from antiselection _____(3)
d. Other (SPECIFY) _____ (4)

19. How likely do you think it is that your HMO will:

| | Very Likely | Somewhat Likely | Somewhat Unlikely | Very Unlikely |
|---|---|---|---|---|
| In the next 5 years: | | | | |
| a. Require genetic testing for applicants with family histories of serious conditions | 1 | 2 | 3 | 4 |
| b. Require carrier tests for applicants at risk of transmitting serious genetic diseases to offspring | 1 | 2 | 3 | 4 |
| c. Require genetic testing for applicants with no known risk to genetic disease | 1 | 2 | 3 | 4 |
| d. Offer optional genetic testing and carrier testing | 1 | 2 | 3 | 4 |
| e. Use information derived from genetic tests for underwriting | 1 | 2 | 3 | 4 |
| f. Alter claims payment practices as new genetic tests come on line | 1 | 2 | 3 | 4 |
| In the next 10 years: | | | | |
| g. Require genetic testing for applicants with family histories of serious conditions | 1 | 2 | 3 | 4 |
| h. Require carrier tests for applicants at risk of transmitting serious genetic diseases to offspring | 1 | 2 | 3 | 4 |
| i. Require genetic testing for applicants with no known risk to genetic disease | 1 | 2 | 3 | 4 |
| j. Offer optional genetic testing and carrier testing | 1 | 2 | 3 | 4 |
| k. Use information derived from genetic tests for underwriting | 1 | 2 | 3 | 4 |
| l. Alter claims payment practices as new genetic tests come on line | 1 | 2 | 3 | 4 |

20. Please indicate whether you:

| | Agree Strongly | Agree Somewhat | Disagree Somewhat | Disagree Strongly |
|---|---|---|---|---|
| a. It's fair for HMOs to use genetic tests to identify individuals with increased risk of disease. | 1 | 2 | 3 | 4 |
| b. An HMO should have the option of determining how to use genetic information in determining risks. | 1 | 2 | 3 | 4 |
| c. Genetic conditions, such as cystic fibrosis or Huntington's disease, are pre-existing conditions. | 1 | 2 | 3 | 4 |
| d. Carrier status for genetic conditions, such as cystic fibrosis or Tay-Sachs, are pre-existing conditions. | 1 | 2 | 3 | 4 |
| e. Genetic information is no different than other types of medical information. | 1 | 2 | 3 | 4 |
| f. Prenatal diagnosis indicates the fetus is affected with cystic fibrosis; the couple decide to continue the pregnancy. The HMO, which paid for the tests, informs the couple they will have no financial responsibility for the cystic fibrosis-related costs for the child. | 1 | 2 | 3 | 4 |
| g. Through prior genetic testing, the husband is known to be a carrier for cystic fibrosis. Before having children, the wife seeks genetic testing for cystic fibrosis. The HMO declines to pay for the testing, since there is no history of cystic fibrosis in her family. | 1 | 2 | 3 | 4 |

**SECTION VI: DEMOGRAPHICS**

21. What is your job title?

    _____

22. Which of the following lines of insurance does your company underwrite?

    Health 1

    Disability 2

    Life 3

23. What percent of persons under HMO policies issued by your company are in policies classified as:

    Self-insured Administration _____%

    Individual _____%

    Community-rated Groups _____%

    Experience-rated Groups _____%

    TOTAL 100%

Thank you very much for your cooperation in answering our questions. We would also like to give you an opportunity to give us as any other opinions, concerns, or suggestions related to genetic testing and insurance that you feel our questions did not address. These comments will be strictly anonymous but may be incorporated in our report to Congress. Please write these comments below.

_____

_____

_____

_____

_____

_____

We have attached a peel-off identification number on the questionnaire. This is the only link between the companies who were sampled and the questionnaires returned. We would prefer that you leave the identification number on the questionnaire when you return it. Our staff will remove the label upon receipt, making the questionnaire entirely anonymous. Absolutely no linkage between companies and questionnaires will be retained. The label from the completed questionnaire is designed to eliminate your company from those that we will have to recontact.

However, if this temporary identification makes you uncomfortable, then peel off the label before returning the questionnaire. We appreciate your help and we want you to feel comfortable in participating in the survey.

_____

**PEEL OFF LABEL WITH SAMPLE**

**IDENTIFICATION HERE**

_____

PLEASE RETURN THE QUESTIONNAIRE IN THE POSTAGE PAID RETURN ENVELOPE SENT WITH THE QUESTIONNAIRE. IF THE ENVELOPE HAS BEEN LOST, THE RETURN ADDRESS IS:

Margaret Anderson
Biological Applications Program
Office of Technology Assessment
U.S. Congress
Washington, DC 20510-8025

## CONGRESSIONAL OFFICE OF TECHNOLOGY ASSESSMENT

### SURVEY OF HEALTH INSURERS' ATTITUDES AND PRACTICES REGARDING GENETIC TESTING FOR CYSTIC FIBROSIS

ATTN: CHIEF UNDERWRITER

Please Respond by July 19, 1991

The Congressional Office of Technology Assessment (OTA) is contacting health insurers who offer individual coverage in a national survey of attitudes and practices regarding cystic fibrosis screening. This questionnaire has been directed to you as the person in your organization whose responsibilities include underwriting. We request your assistance in answering some questions about genetic testing and underwriting in your company. **If you are not the Chief Underwriter, we would appreciate it if you would please forward the questionnaire to the appropriate person.**

For the purposes of this survey, OTA has adopted the following definitions:

> By *carrier testing*, we mean testing an unaffected individual to reveal the possibility that off-spring may have a serious chronic condition or disease (e.g., cystic fibrosis or sickle cell disease).
>
> By *genetic testing*, we mean testing applicants or policyholders for certain inherited characteristics either presymptomatically to reveal future serious chronic disease (e.g., for Huntington's disease) or for risk oriented purposes (e.g., predisposition to heart disease).

This is an important study that has been requested by the U.S. Congress, and is designed to represent the attitudes and practices of health insurers. We need to know how insurers view the technologies of genetic testing in terms of their current and future applications in health insurance.

Please read each question and mark the space that most nearly corresponds to your answer. Please feel free to qualify your answers. Space has been provided at the end for comments and opinions that you feel are not adequately represented by the survey questions. The survey responses will be kept strictly anonymous as well as confidential.

**PLEASE NOTE:** This survey focuses on three health insurance populations---(1) *Medically underwritten Individuals/nongroup* who seek insurance independently and without any association with an employer or membership group of any kind; (2) *Medically underwritten groups*, i.e., those groups whose members must be medically underwritten; and (3) *Nongroup open enrollment*, individuals/nongroup who seek open enrollment coverage, i.e., without medical underwriting.

**********

*Conversions should be excluded from your responses.* In addition, we prefer that you exclude Medigap insurance from your responses. If because of reporting or other reasons, you must include Medigap policies, please check the box below:

[ ] YES, Medigap policies and statistics are included in our responses to this survey.

**********

Does your plan have an open enrollment period? [ ] YES (1) [ ] NO (2)
If yes, is it continuous? [ ] YES (1) [ ] NO (2)

## SECTION I: INDIVIDUAL AND GROUP STATISTICS

| | Individual/Non-group Policies | Medically Underwritten Groups | Nongroup Open Enrollment |
|---|---|---|---|
| 1. What is the approximate number of persons that you currently insure through: | _____ | _____ | _____ |
| 2. What is the approximate number of applications received by your company per year for coverage under: | _____ | _____ | _____ |
| 3. What portion of those applications are: | | | |
| a. Accepted at standard rates without exclusion waiver or waiting period | _____% | _____% | _____% |
| b. Covered with an exclusion waiver, but standard premium | _____% | _____% | _____% |
| c. Covered with a waiting period, but standard premium | _____% | _____% | _____% |
| d. Covered with a rated/risk-adjusted premium, but not exclusion waiver or waiting period | _____% | _____% | _____% |
| e. Covered with an exclusion waiver and a rated/risk-adjusted premium | _____% | _____% | _____% |
| f. Covered with a waiting period and a rated/risk-adjusted premium | _____% | _____% | _____% |
| g. Declined by your company | _____% | _____% | _____% |
| h. Other (SPECIFY) | _____% | _____% | _____% |
| _____ | _____% | _____% | _____% |
| _____ | _____% | _____% | _____% |
| TOTAL | 100% | 100% | 100% |

SECTION II: UNDERWRITING PRACTICES

4. For each category of coverage, please estimate the proportion of all health insurance applicants from whom you require:

| | Individual/Non-group Policies | Medically Underwritten Groups | Nongroup Open Enrollment |
|---|---|---|---|
| a. A personal health history | _____% | _____% | _____% |
| b. A family health history | _____% | _____% | _____% |

IF A FAMILY HISTORY IS REQUIRED, ON WHOM WOULD INFORMATION BE REQUESTED. CHECK ALL THAT APPLY.

[ ] Spouse (1)
[ ] Parents (2)
[ ] Grandparents (3)
[ ] Siblings (4)
[ ] Children (5)
[ ] Other (SPECIFY) _____ (6)

| | | | |
|---|---|---|---|
| c. An attending physician statement (APS) | _____% | _____% | _____% |

IF AN APS IS REQUIRED FOR ANY INDIVIDUALS, WHICH OF THE FOLLOWING WOULD TRIGGER THE REQUIREMENT. CHECK ALL THAT APPLY.

[ ] Any significant diagnosis or symptoms reported on application (1)
[ ] Selected diagnoses or symptoms reported on application (2)
[ ] Any significant conditions reported in family history (3)
[ ] Selected conditions reported in family history (4)
[ ] M.I.B. report (5)

| | | | |
|---|---|---|---|
| d. Physical exam: | _____% | _____% | _____% |

IF AN EXAM IS EVER REQUIRED, WHICH OF THE FOLLOWING WOULD TRIGGER THE REQUIREMENT. CHECK ALL THAT APPLY.

[ ] Any significant diagnosis or symptoms reported on application (1)
[ ] Selected diagnoses or symptoms reported on application (2)
[ ] Any significant conditions reported in family history (3)
[ ] Selected conditions reported in family history (4)
[ ] M.I.B. report (5)
[ ] Any significant diagnosis or symptoms identified in APS (6)

| | | | |
|---|---|---|---|
| e. Blood or urine screens: | _____% | _____% | _____% |

PLEASE ANSWER THE FOLLOWING QUESTIONS (#5-11) AS THEY APPLY TO YOUR MOST COMMONLY PURCHASED PRODUCT. IS THIS PRODUCT (CHECK ONE):

Traditional _____ (1)
PPO _____ (2)
HMO _____ (3)

5. For each category of coverage, please indicate the importance of each of the following factors in determining insurability (not in rating):

*1 = Very important; 2 = Important; 3 = Unimportant; 4 = Never used*

| | Individual/Non-group Policies | Medically Underwritten Groups |
|---|---|---|
| a. Age | _____ | _____ |
| b. Occupation | _____ | _____ |
| c. Smoking status | _____ | _____ |
| d. Lifestyle | _____ | _____ |
| e. Sex | _____ | _____ |
| f. Financial/credit status | _____ | _____ |
| g. Personal medical history of significant conditions | _____ | _____ |
| h. Family medical history of significant conditions | _____ | _____ |
| i. Genetic predisposition to significant conditions | _____ | _____ |
| j. Carrier risk for genetic diseases | _____ | _____ |

6. For each category of coverage, how would you normally treat these policies if they disclosed the following conditions in an examination(s) or application:

*1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;*
*3 = Accepted with waiting period at standard rates;*
*4 = Accepted with exclusion waiver at rated/risk-adjusted premium;*
*5 = Accepted without exclusion waiver or waiting period but at rated/risk-adjusted premium;*
*6 = Accepted with waiting period at rated/risk-adjusted premium; 7 = Declined*

| | Individual/Non-group Policies | Medically Underwritten Groups | Nongroup Open Enrollment |
|---|---|---|---|
| a. Hypertension | _____ | _____ | _____ |
| b. Diabetes mellitus | _____ | _____ | _____ |
| c. Cerebrovascular disease | _____ | _____ | _____ |
| d. Hemophilia | _____ | _____ | _____ |
| e. Sickle cell anemia | _____ | _____ | _____ |

**SECTION III: GENETIC CONDITIONS**

7. Does your company specifically inquire, for each category of coverage, about the following conditions in the application for health insurance in the personal history, family history, or neither:

*1 = Personal history only; 2 = Family history; 3 = Neither*

| | Individual/Non-group Policies | Medically Underwritten Groups | Nongroup Open Enrollment |
|---|---|---|---|
| a. Hemophilia | _____ | _____ | _____ |
| b. Tay-Sachs | _____ | _____ | _____ |
| c. Huntington's disease | _____ | _____ | _____ |
| d. Sickle cell anemia | _____ | _____ | _____ |
| e. Cystic fibrosis | _____ | _____ | _____ |
| f. Any other genetic disease (SPECIFY) | _____ | _____ | _____ |

8. For individual policy applicants only, how would the application normally be treated if a policy applicant was asymptomatic but had a family history of:

*1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;*
*3 = Accepted with waiting period at standard rates;*
*4 = Accepted with exclusion waiver at rated/risk-adjusted premium;*
*5 = Accepted without exclusion waiver or waiting period but at rated/risk-adjusted premium;*
*6 = Accepted with waiting period at rated/risk-adjusted premium; 7 = Declined*

| | Individual/Non-group Policies |
|---|---|
| a. Hemophilia | _____ |
| b. Tay-Sachs | _____ |
| c. Huntington's disease | _____ |
| d. Sickle cell anemia | _____ |
| e. Cystic fibrosis | _____ |
| f. Duchenne muscular dystrophy | _____ |
| g. ADA deficiency ("Bubble Boy disease") | _____ |
| h. Down Syndrome | _____ |

9. For individual policy applicants only, how would the coverage of a family member (e.g., spouse or adopted child) be affected if the policy applicant was negative, but the family member was asymptomatic but had a family history of:

*1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;*
*3 = Accepted with waiting period at standard rates;*
*4 = Accepted with exclusion waiver at rated/risk-adjusted premium;*
*5 = Accepted without exclusion waiver or waiting period but at rated/risk-adjusted premium;*
*6 = Accepted with waiting period at rated/risk-adjusted premium; 7 = Declined*

| | Individual/Non-group Policies |
|---|---|
| a. Hemophilia | _____ |
| b. Tay-Sachs | _____ |
| c. Huntington's disease | _____ |
| d. Sickle cell anemia | _____ |
| e. Cystic fibrosis | _____ |
| f. Duchenne muscular dystrophy | _____ |
| g. ADA deficiency ("Bubble Boy disease") | _____ |
| h. Down Syndrome | _____ |

10. For each category of coverage, do your standard policies provide coverage for:

*1 = At patient request; 2 = Only if medically indicated; 3 = Not covered*

| | Individual/Non-group Policies | Medically Underwritten Groups | Nongroup Open Enrollment |
|---|---|---|---|
| Carrier tests for: | | | |
| a. Cystic fibrosis | _____ | _____ | _____ |
| b. Tay-Sachs | _____ | _____ | _____ |
| c. Sickle cell trait | _____ | _____ | _____ |
| Prenatal tests for: | | | |
| d. Cystic fibrosis | _____ | _____ | _____ |
| e. Tay-Sachs | _____ | _____ | _____ |
| f. Sickle cell anemia | _____ | _____ | _____ |
| g. Down Syndrome | _____ | _____ | _____ |
| h. Other (SPECIFY) | _____ | _____ | _____ |
| Genetic counseling | _____ | _____ | _____ |

11. For each category of coverage, how would these policies normally be affected by the following findings:

*1 = Accepted with standard rates; 2 = Accepted with exclusion waiver at standard rates;*
*3 = Accepted with waiting period at standard rates;*
*4 = Accepted with exclusion waiver at rated/risk-adjusted premium;*
*5 = Accepted without exclusion waiver or waiting period but at rated/risk-adjusted premium;*
*6 = Accepted with waiting period at rated/risk-adjusted premium; 7 = Declined*

| | Individual/Non-group Policies | Medically Underwritten Groups | Nongroup Open Enrollment |
|---|---|---|---|
| a. Presymptomatic testing reveals the likelihood of a serious, chronic future disease (e.g., for Huntington's disease) | _____ | _____ | _____ |
| b. Risk oriented testing reveals that an individual carries markers associated with a serious, chronic future disease (e.g., predisposition to heart disease) | _____ | _____ | _____ |
| c. Carrier testing reveals the possibility that off-spring may have a serious, chronic condition or disease | _____ | _____ | _____ |
| d. Prenatal diagnosis reveals fetus affected with a serious, chronic condition or disease | _____ | _____ | _____ |

**SECTION IV: GENERAL ATTITUDES**

12. To your knowledge, has your company ever reimbursed for carrier testing for cystic fibrosis?
Yes _____(1)
No _____(2)

13. Has your company ever conducted an economic analysis of the costs and benefits of:

| | Yes | No |
|---|---|---|
| a. Carrier testing as part of applicant screening | 1 | 2 |
| b. Genetic counseling of carriers who are covered | 1 | 2 |
| c. Carrier testing as part of prenatal coverage | 1 | 2 |
| d. Genetic testing as part of applicant screening | 1 | 2 |

14. Under what conditions would a negative financial impact be likely to occur for your company: (CHECK ALL THAT APPLY)

a. Widespread availability of genetic tests to the medical/provider community _____(1)
b. Widespread availability of genetic tests with constraints on insurers' access to the results _____(2)
c. Adverse claims or underwriting results from antiselection _____(3)
d. Other (SPECIFY) _____ (4)

15. How likely do you think it is that your company will:

| | Very Likely | Somewhat Likely | Somewhat Unlikely | Very Unlikely |
|---|---|---|---|---|
| In the next 5 years: | | | | |
| a. Require genetic testing for applicants with family histories of serious conditions | 1 | 2 | 3 | 4 |
| b. Require carrier tests for applicants at risk of transmitting serious genetic diseases to offspring | 1 | 2 | 3 | 4 |
| c. Require genetic testing for applicants with no known risk to genetic disease | 1 | 2 | 3 | 4 |
| d. Offer optional genetic testing and carrier testing | 1 | 2 | 3 | 4 |
| e. Use information derived from genetic tests for underwriting | 1 | 2 | 3 | 4 |
| f. Alter claims payment practices as new genetic tests come on line | 1 | 2 | 3 | 4 |
| In the next 10 years: | | | | |
| g. Require genetic testing for applicants with family histories of serious conditions | 1 | 2 | 3 | 4 |
| h. Require carrier tests for applicants at risk of transmitting serious genetic diseases to offspring | 1 | 2 | 3 | 4 |
| i. Require genetic testing for applicants with no known risk to genetic disease | 1 | 2 | 3 | 4 |
| j. Offer optional genetic testing and carrier testing | 1 | 2 | 3 | 4 |
| k. Use information derived from genetic tests for underwriting | 1 | 2 | 3 | 4 |
| l. Alter claims payment practices as new genetic tests come on line | 1 | 2 | 3 | 4 |

16. Please indicate whether you:

| | Agree Strongly | Agree Somewhat | Disagree Somewhat | Disagree Strongly |
|---|---|---|---|---|
| a. It's fair for insurers to use genetic tests to identify individuals with increased risk of disease. | 1 | 2 | 3 | 4 |
| b. An insurer should have the option of determining how to use genetic information in determining risks. | 1 | 2 | 3 | 4 |
| c. Genetic conditions, such as cystic fibrosis or Huntington's disease, are pre-existing conditions. | 1 | 2 | 3 | 4 |
| d. Carrier status for genetic conditions, such as cystic fibrosis or Tay-Sachs, are pre-existing conditions. | 1 | 2 | 3 | 4 |
| e. Genetic information is no different than other types of medical information. | 1 | 2 | 3 | 4 |
| f. Prenatal diagnosis indicates the fetus is affected with cystic fibrosis; the couple decide to continue the pregnancy. The health insurance carrier, which paid for the tests, informs the couple they will have no financial responsibility for the cystic fibrosis-related costs for the child. | 1 | 2 | 3 | 4 |
| g. Through prior genetic testing, the husband is known to be a carrier for cystic fibrosis. Before having children, the wife seeks genetic testing for cystic fibrosis. The insurance company declines to pay for the testing, since there is no history of cystic fibrosis in her family. | 1 | 2 | 3 | 4 |

## SECTION V: DEMOGRAPHICS

17. What is your job title?

    _____

18. Which of the following lines of insurance does your company underwrite?

    Health 1

    Disability 2

    Life 3

19. What percent of persons under health insurance policies issued by your company are in policies classified as:

    Self-insured Administration _____%

    Individual _____%

    Small Groups _____%

    Large Groups _____%

    TOTAL 100%

Thank you very much for your cooperation in answering our questions. We would also like to give you an opportunity to give us as any other opinions, concerns, or suggestions related to genetic testing and insurance that you feel our questions did not address. These comments will be strictly anonymous but may be incorporated in our report to Congress. Please write these comments below.

_____

_____

_____

_____

_____

_____

We have attached a peel-off identification number on the questionnaire. This is the only link between the companies who were sampled and the questionnaires returned. We would prefer that you leave the identification number on the questionnaire when you return it. Our staff will remove the label upon receipt, making the questionnaire entirely anonymous. Absolutely no linkage between companies and questionnaires will be retained. The label from the completed questionnaire is designed to eliminate your company from those that we will have to recontact.

However, if this temporary identification makes you uncomfortable, then peel off the label before returning the questionnaire. We appreciate your help and we want you to feel comfortable in participating in the survey.

_____

**PEEL OFF LABEL WITH SAMPLE**

**IDENTIFICATION HERE**

_____

PLEASE RETURN THE QUESTIONNAIRE IN THE POSTAGE PAID RETURN ENVELOPE SENT WITH THE QUESTIONNAIRE. IF THE ENVELOPE HAS BEEN LOST, THE RETURN ADDRESS IS:

Margaret Anderson
Biological Applications Program
Office of Technology Assessment
U.S. Congress
Washington, DC 20510-8025

# Appendix D
# Acknowledgments

OTA would like to thank the members of the advisory panel and extemal reviewers for their review of draft materials related to this background paper during the course of the assessment, *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening*. In addition, OTA acknowledges the following additional reviewers and workshop participants for their assistance in developing and reviewing drafts of the survey instrument:

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***Cystic Fibrosis, Genetic Screening, and Insurance***
***February 1, 1991***

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# Appendix E
# Acronyms and Glossary

## *Acronyms*

APS —attending physician statement
BC/BS —Blue Cross and Blue Shield
DNA —deoxyribonucleic acid
GHAA —Group Health Association of America
HIAA —Health Insurance Association of America
OTA —Office of Technology Assessment
MIB —Medical Information Bureau, Inc.

## *Glossary of Terms*

**Adverse selection:** The tendency of persons with poorer than average health expectations to apply for or continue insurance to a greater extent than persons with average or better health expectations. Also known as "antiselection."

**Allele:** Alternative variants of a gene that occur at a given site (e.g., at a site for eye color there might be alleles resulting in blue or brown eyes); alleles are inherited separately from each parent.

**Carrier:** An apparently unaffected individual who possesses a single copy of a recessive gene obscured by a dominant allele; a heterozygote.

**Community rating:** A method of determining premium rates based on the allocation of total costs without regard to past group experience. Community rating is required of federally qualified health maintenance organizations.

**Cystic fibrosis (CF):** A life-shortening, recessive disorder affecting the respiratory, gastrointestinal, reproductive, and skeletal systems, as well as the sweat glands. CF is caused by mutations in the CF gene that affect the CF gene product, cystic fibrosis transmembrane conductance regulator (CFTR). Individuals with CF possess two mutant CF genes.

**Cystic fibrosis carrier:** An individual who possesses one CF mutation and one normal CF gene. CF carriers manifest no symptoms of the disorder. See *carrier.*

**Cystic fibrosis carrier screening:** The performance of tests on persons for whom no family history of CF exists to determine whether they have one aberrant CF gene and one normal CF gene. See *cystic fibrosis screening.*

**Cystic fibrosis screening:** The performance of tests to diagnose the presence or absence of the actual disorder, in the absence of medical indications of the disease or a family history of CF. Many States screen newborns for genetic disease, but only Colorado and Wisconsin routinely screen for CF. See *cystic fibrosis carrier screening.*

**Deoxyribonucleic acid (DNA):** The molecule that encodes genetic information. DNA is a double-stranded helix held together by weak bonds between base pairs of nucleotides.

**DNA:** See *deoxyribonucleic acid.*

**Dominant:** In genetics, referring to a situation where only one copy of an allele is necessary for the effect (e.g., disease) to be expressed.

**Genetic counseling:** A clinical service involving educational, informational, and psychosocial element to provide an individual (and sometimes his or her family) with information about heritable conditions. Genetic counseling is performed by genetics specialists, including physicians, Ph.D. clinical geneticists, genetic counselors, nurses, and social workers.

**Genetic test:** An assay to reveal whether an individual has an inherited disorder, predisposition to such a disorder, or is a carrier for one.

**Health maintenance organization (HMO):** A health care organization that serves as both payer and provider of comprehensive medical services, provided by a defined group of physicians to an enrolled, fee-paying population.

**Huntington disease:** A chronic, dominant inherited disorder characterized by involuntary movements of the extremities and progressive dementia; age of onset is usually between 40 and 50 years of age.

**Open enrollment:** A health insurance enrollment period during which coverage is offered regardless of health status and without medical screening. Open enrollment periods are characteristic of some Blue Cross and Blue Shield plans and health maintenance organizations.

**Preexisting condition:** A condition existing before an insurance policy goes into effect and commonly defined as one which would cause an ordinarily prudent person to seek diagnosis, care, or treatment.

**Prenatal testing:** Assay performed after conception but before birth—usually via amniocentesis or chorionic villus sampling—to assess the status of the fetus.

**Rated premium:** A premium with an added surcharge that is required by insurers to cover the additional risk associated with certain medical conditions. Rated premiums usually range from 25 to 100 percent of the standard premium.

**Recessive:** In genetics, referring to a situation where two copies of an allele are necessary for the effect (e.g., disease) to be expressed.

**Sickle cell anemia:** A recessive disorder affecting red blood cell flow through the circulatory system, causing complications in numerous organ systems. Sickle cell anemia predominantly occurs in individuals of African descent.

**Sickle cell trait:** Sickle cell carrier status.

**Single-gene disorder:** Hereditary disorder caused by a single gene (e.g., CF, Huntington disease, Tay-Sachs disease, sickle cell anemia).

**Tay-Sachs disease:** A lethal, recessive disorder affecting the central nervous system which results in mental retardation and early death. Tay-Sachs disease predominantly occurs among Jews of Eastern and Central European descent and populations in the United States and Canada descended from French Canadian ancestors.

**Underwrite:** The process by which an insurer determines whether and on what basis it will accept an application for insurance.

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## Office of Technology Assessment

The Office of Technology Assessment (OTA) was created in 1972 as an analytical arm of Congress. OTA's basic function is to help legislative policymakers anticipate and plan for the consequences of technological changes and to examine the many ways, expected and unexpected, in which technology affects people's lives. The assessment of technology calls for exploration of the physical, biological, economic, social, and political impacts that can result from applications of scientific knowledge. OTA provides Congress with independent and timely information about the potential effects—both beneficial and harmful—of technological applications.

Requests for studies are made by chairmen of standing committees of the House of Representatives or Senate; by the Technology Assessment Board, the governing body of OTA; or by the Director of OTA in consultation with the Board.

The Technology Assessment Board is composed of six members of the House, six members of the Senate, and the OTA Director, who is a nonvoting member.

OTA has studies under way in nine program areas: energy and materials; industry, technology, and employment; international security and commerce; biological applications; food and renewable resources; health; telecommunication and computing technologies; oceans and environment; and science, education, and transportation.

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